FRCH RESEARCH REPORT

SOCIAL ASPECTS OF LEPROSY

findings from rural maharashtra

Sponsored by the Damien Foundation

RAVI DUGGAL
AMAR JESANI
MANISHA GUPTE

MARCH 1988

frch Foundation for Research in Community Health

FOUNDATION FOR RESEARCH IN COMMUNITY HEALTH.

The Foundation was established in 1975 as a research institute in the field of health care with special emphasis on the socio-economic and cultural factors which affect the delivery of services. The following are the objectives:

* To collect collate and analyse available data on the problems of health and illness of our people from the family and community to the national level, in both rural and urban areas.

* To study the cost effectiveness of various models being used in India and other countries.

* To evolve alternative models and methods wherever necessary, which may be more suitable for generalised use in our country -special attention being paid to social, educational, economic and factors which are as important as medical technology in the delivery of health care.

* [redacted]iments to test the feasibility of the new

[redacted]

[redacted]ducate people in the problems affecting their
[redacted]lp as well as proper utilisation of available
[redacted]l services.

[redacted] policy.

[redacted]th movement.

[redacted]YA SHIKSHAN KENDRA

[redacted] Malshiras village is a field based action
[redacted] for Research in Community Health. The study
[redacted]ne Purandar taluka (tehsil) of Pune district
[redacted] population of 30,000 spread over 18 villages.
[redacted] the Primary Health Centre in Malshiras.

[redacted]tion project, sponsored by the Indian Council
[redacted]ot have any service component. Over the next
[redacted] Malshiras would learn people's perceptions
[redacted]th problems and would initiate discussion and
[redacted]ions of the population about health and

[redacted]oject would be :

[redacted] of learning and the means of communicatio

* To identify potential educators and catalysts in the local population

* To initiate a learning process about the varied aspects of healt among the people.

* To work in cooperation with the Primary Health Centre and to involv the government health staff in this process.

* To collect primary and secondary data at the field level and t conduct research projects.

* To evaluate at the end of five years the impact, if any, of th education on the access and utilisation of health services.

COMMUNITY HEALTH CEL
Mark's Road

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ABBREVIATIONS

ANM	: Anxiliary Nurse Midwife
CHV	: Community Health Volunteer
df	: degrees of freedom
FRCH	: Foundation for Research in Community Health
GMLF	: Gandhi Memorial Leprosy Foundation
ICMR	: Indian Council of Medical Research
LCU	: Leprosy Control Unit
MPW	: Multi-Purpose Worker
N (in Tables)	: Number of cases
NGO	: Non-Government Organisation
NLCP	: National Leprosy Control Programme
NLEP	: National Leprosy Eradication Programme
PHC	: Primary Health Centre
SC	: Scheduled Castes
SET	: Survey Education and Treatment
ST	: Scheduled Tribes
TDR	: Tropical Disease Research (of WHO)
ULC	: Urban Leprosy Centre
UNDP	: United Nations Development Programme
WB	: World Bank
WHO	: World Health Organisation
X^2	: Chi square

ACKNOWLEDGEMENTS

This study has been sponsored by the Damien Foundation. We thank them for their financial support.

Dr. Patricia Rosenfield and Prof. R.K. Mutatkar have shown personal interest in this study and had helped us formulate this study. At a later stage their comments have been very useful. We greatly appreciate their interest in our study and thank them for it.

We are grateful to Dr. M.Y. Yellapurkar, Joint Director (leprosy), Directorate of Health Services, and his staff; the Medical Officers and other health workers at the PHCs, Sakharpa, (Ratnagiri Dist.), Adool, Wadigodri (Aurangabad Dist.), Sirur, Wagholi, Nhavara, Kondur (Pune Dist.), Sangvi (Dhule Dist.) and the Medical Officers and staff at the Leprosy Control Unit, Brahmapuri (Chandrapur Dist.). Without their cooperation our study would not have been possible.

Special thanks to Dr. S.P. Tare, Director, Gandhi Memorial Leprosy Foundation (Wardha), Mr. Vijay Narkar, of MatruMandir (Deorukh, Ratnagiri), Sister Cecily of Anandsadan Health Centre (Shripur, Dist. Dhule), Dr. Ashok Dyalchand, Director, Comprehensive Health and Development Project (Pachod, Dist. Aurangabad) and Dr. (Mrs.) Banoo Coyaji, Director, Vadu Rural Health project (Vadu, Dist Pune), who were most kind and helpful in having us carry out study in their field area. We must not forget the staff of these NGOs who readily discussed in detail various activities of their projects and helped us in many ways. Their hospitality also needs acknowledgement.

Dr. Mukund Uplekar, who accompanied us on field work in the high endemic areas was most helpful because of his special experiance in the field of leprosy. He also helped in designing the Patient Interview Schedule. Our most sincere thanks to him.

We thank Sunita Vichare who has most patiently word-processed this document draft after draft without knowing when it would end.

Special thanks also to Manish Mankad and Saraswathy Ananthram of FRCH for handling the technical tasks of page-making and taking it to the final stage of printing. Manish also helped us in troubleshooting when we got stuck with the computer. Thanks to him for that too.

And finally we thank Dr. N.H. Antia, Director of FRCH, under whose guidance this research study has been undertaken. His support and special interest in the study has been a source of encouragement for us. He has gone through each and every sentence that we have written and offered detailed comments, including long hours of discussion. We thank him for that.

FOREWORD

The Indian Council of Medical Research (ICMR) commissioned the Foundation for Research in Community (FRCH) to undertake a study of non-governmental organizations (NGOs) working in the field of health in the state of Maharashtra. The study was undertaken by three senior researchers over a period of three years (1983-86).

This NGO study which was carried out in 18 villages in four districts and compared the health care services offered by the NGOs with the adjacent government Primary health Centers. While the study focused on the overall health problems, the preliminary information indicated that such an indepth study by senior investigators who lived and worked in the field could also provide useful information about leprosy. This was discussed with Dr. Patricia Rosenfield of the Tropical Diseases Research Programme of the World Health Organization during her visit to our Foundation. and a research proposal was sent to the Damien Foundation who readily agreed to provide the additional funds needed for this study.

The Districts of Ratnagiri, Dhule, Aurangabad and Pune included in the ICMR study are low endemicity areas of leprosy. Hence it was decided to extend this study to include two high endemic districts - Wardha & Chandrapur. It was also felt that the comparison between the latter two districts would give us comparative information of an area where there has been intensive leprosy work by a NGO - the Gandhi Memorial Leprosy Foundation, Wardha - especially health education and a backward area where leprosy work has been nowhere of similar intensity and undertaken only under the aegis of the government leprosy programme (in Chandrapur).

We feel that this study undertaken at the grass root level by senior researchers with a strong social science background provides a new understanding to some aspects of leprosy especially those concerning the patients as well as the society in which they live. It is hoped that the findings of this study, especially those related to health education may make the government and NGOs pause and reconsider before new inputs are made in this field.

We are grateful to the Damien Foundation for supporting this study.

FRCH, Bombay
3rd March, 1988

DR. N.H. ANTIA
DIRECTOR

GLOSSARY

Community : Religious groups like Hindus, Muslims.

Caste : The caste stratification of Hindus is used in a Broad framework. In each caste, certain non-Hindu strata having similar social status as some of the established Hindu caste are also included. The broad caste classification used is as follows:

- Upper Caste Hindus : Brahmins, Marathas, Kunbis, Marwaris, Jains.
- Scheduled Castes : All scheduled castes, Neo-buddhists, "Scheduled Caste" Christians.
- Other Hindu Castes : All other Hindu Castes not included in above two categories.

Scheduled Tribes : All Tribals irrespective of their religious beliefs.

Landholding : Amount of land owned by the household. It is classified into the the following classes:

- Landless : Households without any agricultural land
- Marginal and Small or poor farmers/ Peasants : Household having land-holding upto 5 acres.
- Middle Peasants/ Farmers : Household with landholding more than 5 acres but upto 20 acres.
- Rich Peasants/ Farmers : Households with landholding more than 20 acres.

Education : Completed years or standards of schooling

X^2 values : Highly significant - p beyond .01
Singnificant - p beyond .05 but below .01
Not significant - p below .05

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SUMMARY

MARCH 1988

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SUMMARY OF FINDINGS

The present study began as an add on to an ICMR research project which focused on the NGO health sector in rural Maharashtra. The main objective of this project was to critically evaluate NGO intervention from a comparative perspective. The opportunity that this major study offered in establishing direct contact with a representative rural population led to the inclusion of a study to look into the `social aspects of leprosy´. The Damien Foundation willingly agreed to provide additional funds to conduct the leprosy study.

* * * * * * *

Leprosy as a disease has a unique feature in the sense that unlike most other diseases it stigmatises the afflicted person. This study aims at exploring and critically understanding the socio-cultural, economic and political correlates of this stigmatising disease. The study has been carried out in both leprosy high endemic and low endemic areas and focuses around differentials, if any, due to endemicity.

The study places stigma in the context of political economy and the entire social structure. It rejects the behaviourist approach and examines the stigma against leprosy in terms of the general discrimination existing in an exploitative society - a society in which the basis of relations of production are differentiation, discrimination, domination, alienation and ostracism.

It is often suggested that the main cause of stigma, historically, has been the inability to tackle the disease in any significant manner. And the disfigurement that is often associated with it has only helped cement the stigma. This explanation is rejected by the authors. Stigma is socially acquired and is reproduced in society as a part of the process of reproduction of inequality. For instance stigma against leprosy cannot be viewed independent of casteism and untouchabillty, racism and skin colour, class society and the working class. Health education that is aimed at modifying behaviour by appealing to rationality has failed to eliminate stigma, because like inequality persists in a society of abundance so irrationality persists in the modern scientific age. Therefore the fight against stigma of leprosy has to be a fight to change radically the social reality itself.

* * * * * * *

The National Leprosy Control Programme started in 1954 has over the years failed to make any significant dent in controlling leprosy. The Survay Education & Treatment (SET) approach adopted under National Leprosy Control Programme (NLCP) to run a vertical programme of national importance has paid poor dividends, except in small pockets of a few states often with active participation of some NGOs. The top-down approach of the programme and a disinterested bureaucracy is the first stumbling block. Policies and programmes are formulated on the basis of ideas that have little or no connection with the context of socio-cultural and economic aspects of the placement of the disease in people's lives. The status accorded to the leprosy programme and as a consequence to those who work in it is very low. This low status is directly related to the stigma associated with the disease as well as to its low priority in the health system. There is a deep-seated stigma against the leprosy programme within the health service organization, and postings to the leprosy programme are considered as a "punishment -posting". The weakest element of NLCP's SET approach is the education component.

* * * * * * *

The survey was carried out in 22 villages spread over six districts. Four villages of two districts (Wardha & Chandrapur) have high endemicity of leprosy and 18 villages from four districts (Ratnagiri, Pune, Aurangabad and Dhule) have low endemicity. The prevalence rate in the high endemic sample was 14.68 leprosy patients per 1000 population and 1.6 per 1000 in the low endemic sample.

The principal objective of the study was to explore and understand stigma assoicated with leprosy, both from the perspective of the patient and the general population. This has undertaken in a comparative framework between the high and low endemic samples, as well as evaluating the effects of intervention of a NGO in the high endemic area. All the registered patients from these 22 villages and persons from randomly selected households were interviewed using quasi-structured interview schedules.

* * * * * * *

Characteristics of the Sample: The high and low endemic area populations differ significantly on the basis of two important characteristics - caste distribution and landholding distribution. These two variables are prime determinants of social and economic status. In the low endemic area the middle castes (Marathas) constitute the dominant group but in the high endemic area the occupational castes (balutedars) constitute a large majority. This distribution has resulted in a highly significant chi-square value. Similarly in the case of landholding the chi-square value is highly significant because in the high endemic area the landless form a large proportion in comparison to the middle peasantry in the low endemic area. These two differentials are very important indicators in understanding and explaining differentials if any, regarding leprosy stigma and related aspects. Educational achievement is also an important variable but between the two areas there is no significant difference in the spread of this characteristic. However, when education is seen in the context of caste and landholding status it presents significant differences showing a direct relationship i.e. a better recognised social status (high caste) and a higher economic status (large landholding) are important determinants for access to higher levels of education.

Knowledge of leprosy: As anticipated knowledge of leprosy is significantly different between the low and high endemic areas. Respondents from the high endemic area were better informed about the disease. They not only knew about the disease but cited its symptoms and signs correctly more often. High endemicity is largely responsible for this difference. Because of the high prevalence people get to see a lot more leprosy in the high endemic area. The distribution of other socio-economic factors (caste, landholding and education) show that with regard to knowledge about leprosy these factors don't matter in the high endemic area but are very important in the low endemic area. This is because high prevalence of the disease makes the knowledge universal - cutting across socio-economic factors. Whereas in the low endemic area the "upper" castes, the richer peasants and the more educated classes have better knowledge about leprosy simply because their position in society makes access to information, whether correct or incorrect, more possible.

Stigma against leprosy: We began with the hypothesis that because of high prevalence in the high endemic areas (as every other household may have a leprosy patient) the stigma against leprosy (at least physical expression) would be absent or significantly lower as compared to the low endemic areas where we also expected secrecy about the disease to be higher. This hypothesis has been disproved. Even when we control the distribution for socio economic factors we find that no significant differences show. This helps us in reaching the conclusion that stigma against leprosy is almost universal: that not only people living in high and low endemic areas share similar attitudes and feelings with regard to leprosy but also stigma is shared similarly by people from different economic, social and educational backgrounds.

The main reasons given by respondents with regard to why they uphold stigma against leprosy are fear of contracting leprosy and the fear of being ostracised or socially boycotted for associating with leprosy patients. The reasons given in both the high and low endemic areas is similar.

* * * * * * *

PATIENT AND SOCIETY

Characteristics of patients: In the high endemic area the mean age of the patient was significantly lower than the low endemic area. This is because high prevalence affects a wider range of population and in a low prevalence area the disease manifests itself in a higher age group. Similarly a larger proportion of women (though not statistically significant) have contracted leprosy when compared with low endemic area patients. However males constitute as a significant majority of patient population in both the areas. Eighty-two percent of the patients had "ever-married" and out of those who were "never-married" 31% said that they could not get married because they had leprosy. Further, on the basis of caste and landholding the two patient populations are significantly different. In the high endemic area the scheduled caste and tribes and the small peasantry as a class have a significantly higher proportion of patients, whereas in the low endemic areas the "upper" castes and the landless class have a higher proportion of patients.

Patients Experience of the Disease: Experiences of patients pertaining to the onset of the disease, the symptoms and signs experienced, treatment of the disease, advice about disease, treatment, diet, cure, deformity etc, given by the health staff, have been discussed in this section. The findings reveal that the experiences of the patients in both the areas is not very different. "Patch" is the most important onset symptom reported in both areas and a similar proportion of patients in both areas have reported it. However, surprisingly, the proportion of those reporting deformity as an onset symptom is higher in the high endemic area inspite of the fact (as seen earlier) that knowledge is significantly better in the high endemic area.

The patients from both areas have shared similar experiences vis-a-vis advice given to them about the disease, its treatment and cure, diet etc. More than 3/4ths of patients in both areas have stated that no advice or information whatsoever was given to them by the health staff who examined and treated them.

The only significant difference was with regard to regularity of treatment. In the high endemic areas where an LCUS operated the regularity of treatment was significantly better than the low endemic areas. This is expected because of the special emphasis provided for leprosy control in the high endemic area. However, inspite of the high profile leprosy activity in the high endemic area only 51.4% of the patients were taking treatment regularly. In the low endemic area 31.5% of patients were regular. The main reason given for irregularity of treatment or "no treatment currently" is irregular supply of drugs or an inconveniently located health centre. In the low endemic area 80% of the irregular patients gave this reason and in the high endemic area 46% did so. This reflects on the poor performance of the NLCP, even in the high endemic areas where special inputs are made available. Infact, of the SET approach the survey and education components are conspicuous by their absence.

Patient's Interface with society: We have seen earlier that stigma against leprosy is almost universal. But when we asked patients about their interactions in society in different situations they said that things had not changed after they got leprosy. This would appear contradictory. But maybe not, because like the harijans the leprosy patients take their defined position for

granted or accept it as normal, and therefore don't regard the discrimination, if any, as unusual. Also, the limitation of the survey method to study a problem like leprosy when compared to life-history analysis (which we haven't done) could be responsible for this contradiction.

However, interestingly, the only change that the patients have reported has been with regard to interaction with the health staff. Over one-third of the patients in both areas have reported negative changes in interaction with the health staff. The changes were of two types i) refusal to examine or see the patients and ii) not giving proper information or advice about the disease.

* * * * * * *

NGO INTERVENTION

The Gandhi Memorial Leprosy Foundation, Wardha, has been taken up as a case study of a NGO which has done significant work in controlling leprosy.

The GMLF has been running a LCU in that area since 1951, besides a Leprosy Referral Hospital, Training and research centre for leprosy started in later years.

In what manner has the GMLF's intervention effected significant changes in controlling leprosy and destigmatising it?.

The findings reveal that the GMLF has successfully controlled the prevalence of leprosy. They have brought down the prevalence from 25 per 1000 population in 1954 to 8 per 1000 presently. In our survey we recorded a prevalence rate of 6.36 patients per 1000 population in the GMLF sample.

In the government run LCU at Brahmapuri, with which we have compared the GMLF performance, the prevalence rate was 22 per 1000 population. Further, early detection in the GMLF area has been

facilitated by regular surveys. This is substantiated by the fact that not even a single patient in the GMLF area reported the onset symptom as deformity unlike the Brahmapuri LCU area where 16% of the patients had reported deformity as an onset symptom.

With regard to regularity of treatment all the GMLF area patients reported regular treatment whereas only 41% in the Brahmapuri LCU area did so.

However with regard to knowledge, stigma and related aspects, aspects there were no differences between the GMLF and Brahmapuri area. This is another unexpected result. Knowledge of leprosy, stigma, related variables, attitude of health worker towards patient have a more or less similar pattern in both the areas. This shows that the only significant difference that the NGO has made is in making the delivery system more effective. Therefore its contribution has been largely of a techno-managerial nature.

This also raises questions regarding the much talked about health education. GMLFs intensive information and education campaign to change the behavioural response of people towards leprosy and its patients has not paid any significant dividends. This provides evidence for the failure of the behavioural approach to tackle the problem of leprosy stigma. It calls for a need to look at more radical changes - changes that eliminates the discriminating and differentiated social structure itself.

SECTION ONE : INTRODUCTION

1. A CRITIQUE OF STIGMA AND LEPROSY CONTROL

The Political Economy of Stigma

What is stigma?

Stigma in the Social Context

Social Aspects of Leprosy

Leprosy Control

A Note on the National Leprosy Eradication Programme

2. OBJECTIVES, STUDY DESIGN AND METHODOLOGY

Objectives of the Study

Study Design and Methodology

Sampling

Data Collection

Data Analysis

A CRITIQUE OF STIGMA AND LEPROSY CONTROL

Cultural traditions and social practices pertaining to health and medicine have, in recent years, acquired a great significance. This is consequent to an increasing interest in the social sciences about health related issues. Infact the primary health care approach and `community health´ are results of this interaction between the health and social sciences.

Historically, every social system has evolved its healing system providing for sick roles, healers and an accompanying ideology (see Parsons, 1951). Invariably the process of healing has been associated with values of the sacred and divine; as a consequence it has been operated and controlled by an elite class (priestly class in India). Even secularization into the modern system of healing has not demystified the healing system and neither has it rid itself of its elitism.

Every healing system has had its limitations in that it has been incapable of coping with every affliction. But there have always been explanations for grey areas. Whatever was incurable was assigned a metaphysical (or supernatural) cause and was left to the practitioners of the supernatural (sorcerers, exorcists, faith healers etc.) to deal with and offer solutions. **Leprosy** is one such disease which, even today when its cure is well known, is surrounded with awe and is considered generally as manifestation of `god´s wrath´.

Is lack of knowledge or lack of technology the only reason why leprosy enjoys a special (sic) status within our society? Is the stigma and ostracism or isolation associated with leprosy a simple result of this inability to tackle the disease adequately? The answer is no.

The Political Economy of Stigma

What is stigma?

The origin of the term stigma is credited to the Greeks. In their worldly view, it referred to bodily signs designed to

expose something unusual and bad about the moral status of the stigmatised - a blemished person, ritually polluted, to be avoided, especially in public places (Goffman, 1963, p.11). Goffman further adds that later, in Christian times, two layers of metaphor were added to the term : the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin, the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorders. Thus, stigma while segregating the stigmatised individual, invites compassion for such individuals.

Medical historians have paid considerable attention to the stigma attached to leprosy patients. Much of the discussion centres around the time of Biblical antiquity and the early Middle Ages to understand the roots of society's response to leprosy. In Biblical times "lepers" were segregated for it was believed that all impurities were contagious. The "lepers" were considered both unclean and impure. In the early Middle Ages when leprosy became endemic and no treatment proved effective, the Bible was resorted to and segregation became mandatory (Sudhoff, 1917) Similar segregation is also reported from Japan where Buddhism became the dominant religion after its introduction into that country in the 7th century A.D. (Veith, 1947). In India since ancient times, the concepts of purity and pollution were central to the dominant religious and cultural value system and practices.

Goffman classifies three gross categories of stigma:

(1) abomination of the body-the various physical deformities,
(2) blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, dishonesty etc., and
(3) the tribal stigma of race, nation and religion (Goffman, 1963, p.14).

These notions of stigma are socially acquired and the `normal' are expected to observe them. The process of socialisation, and consequently social control, is so encompassing that even the stigmatised (who have been marginalised by society on some count) tend to hold the same beliefs about their identity as the `normals'. This says Goffman, is a pivotal fact. So pivotal that it is the `hook' on which the stigmatized hang all inadequacies, dissatisfactions, procrastinations and all unpleasant duties of social life, depending on it not only as a reasonable escape from competition but as a protection from social responsibility (Baker and Smith, 1939). The `normal' accept these `shortcomings' of the stigmatized and encourage its perpetuation

because stigmatization apparently functions as a means of removing these minorities from avenues of competition. Further, if the stigmatized don't 'behave' in the manner in which they are expected to they arouse suspicion and are brought to book. Thus, stigmatization also becomes a means for social control. The vehicle of stigma are symbols or labels. Labeling is a very powerful social mechanism through which not only attitudes, beliefs, norms and complex behavioral patterns are ingrained but also the entire basis of a class and exploitative society is preserved and reproduced. Stigmatizing of leprosy is part of this larger complex. In one sense the disfigurement that may result from the disease may be directly responsible for the stigma but when we look deeper, it appears as a malaise of the social structure itself.

Stigma in Social Context

There is a broad agreement among sociologists and anthropologists that stigma is a social phenomenon. Stigma is a complex social response to the concrete social reality which is reproduced and changed in the course of historical development. The social basis of stigma is the unequal relationship between individuals and or groups of individuals whose social identity is defined from the stand point of economic and social status, race, sex, health and so on. A social structure based on inequality provides for an economic, social and ideological mechanism to reproduce unequal relationships in the daily life of people. In the course of development, the practical manifestation of stigma changes in accordance with the stage of development, the continuous realignment of socio-economic forces within the structure, and in response to the need to cope with the crises. In the process, new symbols of stigma are added, some of the old ones are modified or discarded. In the society as a whole, various types of stigma co-exist, they influence and modify each other, and all of them together help reinforce inequality in the social intercourse.

Historically, societies have evolved on the basis of the development of their productive forces. Culture, folkways, norms and attitudes have developed as a consequence of these productive forces and the relations of production that dominate within that society. Primitive societies have given way to those whose value systems are based on structural differentiation. This was a result of a new and increasingly complex divison of labour, development of private property and the consequent greater

concentration of ownership of the means of production in fewer hands (see Morgan 1877; and Engels, 1894). The modern capitalist society is based on a newer method of economic exploitation which is continuously reproduced with the help of the political structure evolved from the need of such a society.

Though modern society has evolved modern means of exploitation and oppression, the older forms are not summarily discarded. Rather, the relevant older forms are integrated with the newer ones in such a way that both the forms give a picture of on integrated whole. This also helps in providing an apparent continuity and justification to the modern social order. That is why in a society which has enough productive capacity to meet the needs of all people are deprived of those needs not only on the basis of economic stratification but also in accordance with caste, sex and racial status. The same is true in the field of health where the inability to control diseases, provide safe water, nutrition etc. are termed as "lack of political will", which is nothing but a manifestation of a social system based on inequality.

Inequality in practice is expressed as deprivation and discrimination. Discrimination is deeply ingrained in the daily life in such a way that the perpetrator and the sufferer develop a behavioural pattern to suit the needs of the discriminatory social system, unscientific and irrational nature of such behaviour not with standing. Further, in daily life, all types of discrimination and stigma arising from them are not given equal importance at a given time and place. For example, in racial relations the blacks are discriminated/stigmatised. But in sexual and family relations, women are discriminated irrespective of race. Similarly amongst women, we find the black women discriminated against by the white women. This brings a complexity in the discriminatory relationship.

How does stigma against some diseases articulate within such a discriminatory system? As in the case of economic and/or social status, the stigma against diseases is not uniform, so the intensity of discrimination and stigma against a diseased state depends not only upon the type of disease, it's communicability, ability to treat etc, but above all, the overlap of the disease's manifestation with the cultural and social practices and economic needs. In the case of leprosy, the religio-cultural overlap is the highest and hence the universality and high intensity of stigma.

As human beings evolved from the primitive stages, they brought with them various diseases and in the process acquired new ones. Even presently, the development of modern civilisation is introducing newer diseases and stigma attached to them. Thus, in the course of human development, the diseases ceased to be purely biological phenomena, they acquired social and cultural dimensions as well.

How do human beings respond to diseases? Rubin says, "By necessity man has undoubtedly always been concerned with questions of health and survival, and has sought within the framework of his knowledge solutions to problems of illness" (Rubin 1960, p.785) Therefore, the diseases which not only threatened the biological safety of the individuals but also the social and economic life of the group, and for which no rational solution was available at that time, human beings reacted by isolating themselves, by outcasting the sufferers and so on (Foster and Anderson, 1978, p.34). Infact there are instances in history when such measures helped in controlling epidemics. For example, isolating leprosy patients in leprosaria brought about a sharp decline in the incidence of leprosy in Western Europe during the fourteenth century. This was because in the crowded leprosaria, the undernourished and weak leprosy patients were easy targets for secondary infections. (Sigerist, 1943). Of course this measure actually eliminated leprosy patients rather than leprosy!

How can one explain such human behaviour of eliminating patients and not the disease? Sometimes this is seen as the animal instinct inherited by the humans. After all "Social Darwinism" or the "nothing but" school in anthropology and sociobiology emphasises instinctual continuity of humans with their animal ancestors. We feel that one should refrain from applying biological explanations and theories to social phenomenon; for human evolution introduces the overwhelming social discontinuity to the biological continuity with the animal world. (Reed, 1978). The formation of human society is a unique phenomenon in the living world. The human biological instinct has got more or less reduced to the involuntary processes in the human body. The so-called biological behaviour is in essence the social behaviour of individuals. An animal defense reaction of discarding the diseased is not the same as human social behaviour of depriving and stigmatising some diseased people.

What is important to understand here is the distinction that one ought to make between a social necessity of isolating a

diseased individual in order to reduce or control infection when no good cure is available, and stigmatising or depriving or discriminating an individual for his or her diseased state. This becomes glaring when the cure is available but the society's structure does not allow it to reach to the diseased individual, and when such isolation is not scientifically necessary. **Thus such behaviour is only as much instinctual as is poverty or untouchability or racism.**

To sum up, there is not one reason to explain the relationships of domination. Similarly there is not one reason to explain myths and stigma attached to sufferers and dominated groups, for instance in India to the low caste groups. However all such relationships, myths and stigmas condemn the target individual or groups of individuals to exploitation, oppression or isolation for their taking birth in such oppressed groups or for acquiring certain characteristics, including diseases in the course of living.

The case of leprosy falls in this framework. The isolating and outcasting of the sufferers, misconceptions, myths and stigma attached to it and so on were natural reactions of humanity for its survival. But they also got ingrained in the societal life to be continuously reinforced in the process of reproduction of inequality, exploitation and oppression of groups of people in the society at its various stages. As inequality persists in a society of abundance, similarly irrationality persists in the modern scientific age.

In short, the fight against stigma towards leprosy cannot be an isolated fight. It must be conceived as a part of the attempt to change social reality as a whole.

Social Aspects of Leprosy

Leprosy as an illness exposes those afflicted to a long and protracted experience with pain and sufferring and deformity, as well as social ostracism. Death alone is not the frightening element; the major threat is bodily deterioration and assault on the body-ego (Gussow and Tracy, 1968). Therefore, "it appears reasonable to postulate that it is this complex and its uniqueness which is responsible for the unique social reactions to leprosy (Skinsnes, 1964). Deformity and disfigurement then appears to be the main associate of leprosy to stigma and invariably, deformity is classified as a symptom of the disease (Rao, 1982). Society

and Culture "have seen leprosy as incurable, resulting into deformities, ulcers, changing the very identity of a person into something which is aesthetically devastating and against the cultural image of the body....(afflicting) sinners, worthy of divine punishment".(Mutatkar, 1981).

This then is the dominant view not only in society generally but also among those who have enquired into the `social aspects of leprosy´. However, stigma towards leprosy cannot be looked upon as an independent occurence because its basis is the discriminating, exploitative social system itself. It is thus an ideological issue. The system defines the responses (of its adherents) towards the disease in the same manner as it determined social distance among various groups within its fold. Thus, stigma towards leprosy occurs in the same way as stigma towards the "untouchable" under classical Brahminism, of Stigma towards blacks through racism in South Africa and the USA and most of the "white" world. Moreover this socio-cultural inequality and oppression is reproduced in economic and political relations within society strengthening the adverse relationships between the domineering and the dominated. Consequently a leprosy patient, like the harijan or black, is not only a social outcaste but also suffers economically and politically, being forced into beggary and other activities that are socially looked down upon.

For many years attempts have been made to explain social stigma of leprosy almost exclusively in terms of peoples´ adaptive behaviour. But behaviour is the effect and not the cause of the stigma. All strategies that aimed at merely changing peoples´ behaviour towards leprosy have met with partial success, and these successes have not turned out to be permanent. More importantly, the control of the disease (say bringing its prevalence rate to one or less than one per thousand) has not ushered in societies with people banishing stigma towards leprosy. In Western societies for instance, leprosy is no longer a public health problem, but the masses still harbour stigma towards the disease and its sufferers. The existence of leprosariums and the social, economic and psychological problems faced by their inmates in their societies is documented, although such studies concentrate on the adaptive behaviour to stigmatised illness (Gussow and Tracy, 1968). This also puts to rest the argument that disfiguration of the body is the chief cause of the stigma towards leprosy. In fact, disfiguration is a contributing factor in enhancing the stigma. Hence, the need to eliminate it. But that still does not touch the roots. The social and psychological

problems that leprosy patients face are substantially due to societies defective view of the disease (Ibid), but more importantly due to the defective (discriminating) social system itself.

The **Leprosy Eradication Programme** in India is based on the strategy of Survey, Education and Treatment. The surveys identify the sufferers who are then treated. The role of education is conceived as giving scientific information about the disease to the people and help the sufferer to adapt to the diseased state. The underlying assumption is that once scientific information is received, the people will realise the irrationality of treating leprosy patients as outcastes or untouchables. Change in the attitude of the people can be affected by health education. Health education aimed at informing people about the irrationality of stigma and various superstitions and misconceptions about leprosy may reduce the intensity of stigma and earn leprosy patients some sympathy, but experience shows that it has not been able to eliminate stigma : neither in societies with universal education nor in societies where leprosy has ceased to be a significant disease. As it is often stated by the people involved in leprosy control work, "people receive information, but that doesn't mean they accept it". Furthermore at it's worst, the scientific information in absence of any radical change in social relationships, introduces new symbols to identify stigmatised individuals. To obvious deformities are added skin patches, thickened pinna of the ear and so on. Thus, while giving scientific information, the programme exposes the suffering individual to stigma even earlier. **The purpose of scientific information thus does not turn out to be a social fight against stigma, but a medical decision to detect leprosy.** This is not to argue that early detection is not necessary or scientific information should not be given to the masses. We only intend to point out that social malaise cannot be fought medically alone.

At the same time, social and economic compulsions force groups of people to associate and work with leprosy patients, although they may not believe that there is no harm in associating with them. In brief, such behavioural complexity has its foundations in the socio-economic and cultural reality. Therefore, in order to bring about far-reaching changes in the behaviour, i.e.elimination of stigma, corresponding changes in the socio-economic and cultural life are required to be brought about by eliminating the "stigma" in the social relations itself. In absence of this, imparting of scientific information learnt from

scientific and technological advancement, will at the most reduce or modify the behaviour to generate another complex behavioural pattern.

In order to go into the depth of the problem arising out of stigma towards leprosy, it is necessary to understand it in its innumerable connections, particularly in its relation to various socio-economic conditions. It is necessary to relate various forms of stigma towards leprosy to the social and economic position occupied by the individuals manifesting such stigmatised behaviour. The present study does make efforts in this direction with the objective of acquiring a better understanding of the social basis of leprosy and its stigma.

Leprosy Control

An estimate by WHO (1977) indicates that there are over 12 million leprosy patients in the world, half of which reside in South-East Asia. India accounts for about one-third of all leprosy cases in the world, an estimated 3.95 million cases in 1981. The number of cases of leprosy is expected to increase further as case detection improves; for example, between 1971 and 1981 the number of cases detected in Maharashtra have almost doubled.

India's fight against leprosy began after independence in 1954-55 with the launching of the National Leprosy Control Programme (NLCP). This was based on DDS, a sulphone, discovered as a cheap and effective drug against leprosy. In 1983, following the recommendations of a Working Group appointed under the chairpersonship of Dr. M.S. Swaminathan, the then Member, Planning Commission, the NLCP was converted into the National Leprosy Eradication Programme (NLEP). The Eradication strategy was adopted in reponse to two developments : The advance in chemotherapy with the advent of Rifampicin which reduced the duration of treatment, and the widespread reach of mass media.

The NLEP strategy is based on three components - Survey, Education and Treatment (SET). The very inclusion of education in the strategy of leprosy control shows that health planners recognized its importance early enough. The role of education is conceived as giving scientific information to people about the disease and to help the sufferer adapt to the diseased state. The underlying assumption is that once people receive information they will realize the irrationality of looking upon leprosy patients as

outcastes or untouchables. However, experience of people involved in leprosy control indicates that reception of information is no guarantee to its acceptance.

Thirty years of NLEP have not made any serious dents in the problem of leprosy in India, except in a few isolated pockets in some states through the active participation of a few NGOs, (like the GMLF which has been included as a case study in the present study). This is not to say that the NLEP has achieved no positive results, but to underline the fact that there is more leprosy today than in 1955 and the problem of stigma is as serious. Efforts are presently being made by health planners as well as NGOs and researchers to reevaluate and reconsider the strategy for the control of this as well as other diseases with special emphasis on socio-cultural and economic factors. Even the WHO in 1979 established a scientific working group on social and economic research which includes sociologists, anthropologists, psychologists, among others. These scientists probe peoples' attitudes, perception and behaviour in relation to disease and disease transmission; economists assess, from national and international perspectives, not only the cost-effectiveness of control programmes but also the economic rationale behind decision-making in the household and how it is influenced by and influences disease transmission (UNDP/WB/WHO, 1985). Prof. Mutatkar has summarized this appropriately, "A greater realization is coming to the medical scientists, that the human being can no longer be treated only as an anatomical and physiological entity, but that his individuality should be understood in terms of his culture and belief system. In fact, the individual perceptions of the body image are moulded by the cultural determinants. These factors have necessitated a dialogue between the medical scientists and social scientists, even though the extent of dialogue is limited in nature" (Mutatkar, 1979). This change in perspective was also observed in the last International Congress on Leprosy held in Delhi in 1984. For the first time a whole day was devoted to social and human aspects in the control of leprosy. Whether this changed approach has an impact on the leprosy control programme and in what direction, is yet to be seen.

Prof. D. Banerji commenting on the political economy of leprosy control in a paper presented at the 1984 International Leprosy Congress pointed out that this area of study was practically untouched by social scientists. Political economy concerns the analysis of forces which influences decisions concerning policies, plans and programs .... the low "Status" of

the leprosy program and its workers in the health services ... and the stigma against leprosy in the health services themselves (Banerji, 1984).

The top-down approach of the vertical leprosy program, and its accompanying disinterested bureaucracy is the first stumbling block in the leprosy program. The bureaucratic design inhibits a proper modelling and operation of the leprosy programs, like any other activity of a health care delivery system (Foster, 1982). Policies and programs are formulated on the basis of ideas that have little or no connection with the context of socio-cultural and economic aspects of the placement of the disease in people's lives.

The status accorded to the leprosy program and as a consequence to those who work in it is very low. This low status is directly related to the stigma associated with the disease as well as to its low priority in the health system. As a result implementation of the leprosy program suffers grossly.

This neglect of implementation perhaps offers an explanation of the paradoxical situation in leprosy programs in India : there is a deep-seated stigma against the leprosy program within health service organization and because of this health workers avoid getting posted for leprosy work and those who are unable to avoid doing so, have a low motivation - even antipathy for leprosy work (Rao, 1982). Our discussions with those working in the leprosy program reveals that leprosy is considered a "punishment posting" and leprosy workers, especially physicians, are not only most disinterested in their work but also exhibit stigma towards the disease.

Though education constitutes a significant component of the leprosy program the main focus continues to remain with case-finding and case-holding. This inspite of the realization that socio-cultural and economic factors need to be looked into to bring about changes in community attitudes and practices.

In this study, we have elicited responses from the people on certain forms of stigma. The responses on knowledge of leprosy and leprosy patients has also been elicited. Apart from relating the knowledge of leprosy with their behaviour towards leprosy patients, we have also related both, the knowledge and behaviour to their socio-economic position in society. It should be noted that this attempt is not to provide a very comprehensive

understanding, but within the limitation of the study, to outline one of the methods to study stigma - as a part of the socio-economic structure and to describe it as it exists in the study area.

A NOTE ON THE NATIONAL LEPROSY ERADICATION PROGRAMME

In the last year of the First Five Year Plan (1955-56) the National Leprosy Control Programme (NLCP) (now renamed as the National leprosy Eradication Programme without any change in the overall strategy) was launched in the country. The programme is based on three **principles** :

(i) Detection of all cases, especially those of the infectious types, at as early a stage as possible.
(ii) Provision of treatment facilities to all patients so detected, and
(iii) Health Education to create a favourable atmosphere which will help both in case detection as well as case holding programmes.

The stated **objectives** of the NLEP are :

(a) To reduce the load of infection in the community by converting the bacteriologically positive cases to bacteriological negativity inorder to interrupt the transmission of infection in the community.
(b) To reduce the prevalence rate of leprosy to a level when leprosy will no longer pose major health hazard i.e. less than one case per 1000 population.
(c) Ultimately to rid the country of the disease.

To achieve the objectives, following types of centres have been established:

(1) Survey, Education and Treatment (SET) Centres: They are generally established in rural areas with a prevalence rate of less than 10 per 1000 population and covering about 20,000 to 25,000 population. It is manned by a Leprosy Technician and is supervised by the Medical Officer of the PHC as well as the District Non-medical Supervisor.

(2) Leprosy Control Unit (LCU) : They are generally established in areas with prevalence rate of 10 or above. They cover population of 2 to 4 lacs in rural areas. A medical officer, supervisors and other staff is provided with a vehicle. The main field workers are leprosy technicians, each covering 20 to 25 thousand population.

(3) Urban Leprosy Centre (ULC): Workers on the SET pattern, covering 30 to 50 thousand urban population. A senior para- medical designated as Non-medical Assistant is appointed there with attachment to a Government or Municipal Dispensary/Hospital.

In addition, Temporary Hospitalisation Wards, Reconstructive Surgery Units, Voluntary SET Centres and Leprosy Control Units, Leprosy Training Centres, Leprosy Homes and Hospitals, etc. are set up in the rural and urban areas. The achievement of the physical components of the NLEP in Maharashtra State are given below

NLEP INFRASTRUCTURE IN MAHARASHTRA STATE

PARTICULAR	ACHIEVEMENT (NO.) TILL MARCH 1984
Leprosy Control Unit (LCU)	42
Urban Leprosy Centre (ULC)	211
Survey Education & Treatment Unit (SET)	970
Temporary Hospitalisation Ward	23
Reconstructive Surgery Unit	11
District Leprosy Officer	25
Non-Medical Supervisor	192
Statistical Assistant for SLO	-
Leprosy Training Centre	7
Upgradation of Old Unit	17
Upgradation of Urban Leprosy Centre	23
Upgradation of district Leprosy Office	7
Upgradation of Leprosy Training Centre	5
Maintenance of Voluntary Leprosy Beds	2250
Leprosy Rehabilitation Promotion Unit	2
Sample Survey-cum-Assessment Unit	1

Source : Government of India, Ministry of Health and Family Welfare, "Health Statistics of India - 1984", New Delhi")

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OBJECTIVES, STUDY DESIGN AND METHODOLOGY

The study has been carried out in two parts. This is important to note because of the methodological differences in the two parts of the study.

The first part of the study was planned and carried out as part of an ongoing research project critically evaluating health care services in rural Maharashtra with a focus on non-government organisations (NGOs) in the first six months of 1984. However, unintentionally, the districts selected for the above study were all low endemic areas. In our discussions with Prof. R.K. Mutatkar, (WHO consultant on Social Aspects of Leprosy) and Dr. Patricia Rosenfield (then of WHO TDR) it was felt that it would be important to carry out a comparative study in a high endemic area (this was envisaged in the original research proposal) because, we presumed, that the socio-cultural correlates pertaining to leprosy may be different.

The study carried out in the low endemic areas constituted the first part of the study. We differentiate this study from the second part both because of its limitations and a few methodological differences. However, during the second part of the study we went back to the low endemic study areas to collect additional information using the same methodology as the second part of the study, carried out in the high endemic areas - this has helped narrow down the differences in the methodology of the two parts of the study.

The second part of the study was carried out as an independent study unlike the first part. It is more focused and is also "qualitatively" an improvement over the first part of the study because our experience of the first part of the study helped us in strengthening the research design. However, the basic framework of the study's two parts was unaltered so as to facilitate a comparison between the low and high endemic areas.

Objectives of the Study

The study is focused around stigma associated with leprosy and leprosy patients. Stigma towards leprosy is placed in the socio-cultural and economic context. The study aims to :

a) Understand the stigma associated with leprosy,
b) Study attitudes and practices of people towards leprosy and leprosy patients.
c) Understand the leprosy patients' placement with society society from her/his perspective,
d) Critically assess the functioning of the government's leprosy program as seen by the people and leprosy patients,
e) Document any differentials between high and low endemic areas, and
f) Evaluate the contribution of GMLF (a leprosy NGO) in alleviating stigma associated with leprosy through its health education programs.

STUDY DESIGN AND METHODOLOGY

The study design included two components. Firstly, the general population was interviewed to get an understanding into the various aspects of stigma related to leprosy. Secondly, leprosy patients who were registered with public health services for treatment were interviewed to find out their experience of the disease in all its aspects. Group interviews in the villages from which the sample population and patients were selected were also conducted in order to obtain a wider perspective on the socio-cultural correlates of leprosy. A pilot enquiry revealed that the single most important variable through which stigma was reflected was whether leprosy patients would be allowed to enter a respondent's home. Also, the question of working with a person afflicted with leprosy was important. Therefore, these two variables constitute the central variables of the study as far as stigma is concerned. Where interviews of leprosy patients are concerned, his/her entire experience as a patient - getting or suspecting the disease, diagnosis, treatment, relations with health workers and society has been recorded.

The low endemic area study of leprosy, as indicated earlier, was a small part of a larger study on health care services. The respondents in this sample were thus asked a whole range of questions, and therefore, in a sense the focus was not on leprosy.

Whether this was an advantage or a disadvantage to the study is difficult to tell. But our hunch is that in a low endemic area an enquiry solely on leprosy would be much more difficult to conduct. Infact, as a precaution, even in the high endemic area interview schedule, we placed questions pertaining to leprosy in the middle, preceded by general questions on the household and followed by questions on tuberculosis and general health services.

Sampling

In the low endemic area, since the focus of the study was health services - its knowledge and utilisation, accessibility to the concerned health centre was taken as the criteria for selection of villages from which sample would be drawn. Though state leprosy treatment services are domiciliary, accessibility still remains an important criteria because the health worker should be able to reach the village. Therefore, an equal number of easy and difficult access villages were selected in both high & low endemic areas to both neutralise the role of "access" in our results as well as to examine if "access" accounts for any differential.

In the low endemic area the districts and talukas were selected on the basis of the following criteria: a) that the selection covered areas with different social-geographies to make the sample representative and b) that different dominant typologies (on the basis of method, strategy, objectives and ideology) of NGOs were covered.

In the selection of a high endemic area, we decided to include an NGO that had done significant community based work in the eradication of stigma. The obvious choice in Maharashtra was the Gandhi Memorial Leprosy Foundation (GMLF) in Wardha district. The second high endemic area we selected (to facilitate comparison with GMLF's work in Wardha) was the adjacent district of Chandrapur. In Chandrapur the Bramhapuri LCU was selected randomly from all LCUs in the district.

The selection of the villages in both the high and low endemic areas were done randomly after dividing all the villages in the reference area into easy access and difficult access villages. Easy access was defined as being within 5 kms of the concerned health centre or LCU with public transport facility within 1km walking distance. The rest of the villages, but within 10 kms distance, were considered difficult access.

An equal number of easy & difficult access villages were selected. Within these villages all leprosy patients who were registered with the PHC or LCU were interviewed. In case of the general population, a 20% proportionate caste-landholding stratified random sample (using random number tables) of households was selected in the low endemic area, and 10% of households similarly selected in the high endemic area. The smaller (proportionately) sample in the high endemic area was dictated mainly by constraints of time and resources. However, numerically it was sufficient for the purpose of the study.

The household constitutes the study unit. The interview schedules were administered either to the head of households (if below 55 years) or the next responsible person.

Some characteristics of the respondents interviewed are given in the table below.

SELECTED CHARACTERISTICS OF RESPONDENTS

RESPONDENT CHARACTERISTICS	HIGH ENDEMIC SAMPLE (N=95)	LOW ENDEMIC SAMPLE (N=711)
1. Male Respondents (percent)	91.0	93.0
2. Mean age (years)	44.3 (Range 22-58)	40.6 (Range 18-62)
3. Education (percent)		
a) Never attended school	49.5	56.8
b) Upto 7th class	37.0	34.5
c) Secondary and above	13.5	8.7
4. Occupation (percent)		
a) Nonworkers & housewives	5.3	3.7
b) Mazdoors (daily wage laborers)	46.3	22.8
c) Cultivators	39.0	36.7
d) Petty self-Employed & artisans	4.1	32.6
e) Others *	5.3	4.2

* Others includes industrial workers, service sector employees, Professionals and Businessmen.

DATA COLLECTION

Two separate semi-structured interview schedules were used, one for leprosy patients and the other for the general population.

The leprosy patient schedule was designed to record the total experience of the patient since the time s/he suspected the disease and registered as a patient. Questions administered included identification & diagnosis of the disease, treatment regimen, patient's perception and the patients interaction with society and the health services staff. In-depth interviews with a few patients who were willing to talk freely were also undertaken to provide qualitative support to the structured portion of the study. We must note here that in both the high & low endemic areas we never referred to the patient as a leprosy patient or never used the word leprosy, unless the patient herself/himself mentioned it. Our approach was "we got your name from the health centre as you are taking a long term treatment" and "this disease for which you are taking tablets or treatment" throughout the study.

The other interview schedule canvassed in the general population was directed at exploring the level of knowledge of leprosy and the nature of stigma that existed in the community. Questions pertaining to general socio-economic background and health care services were also included alongwith those on leprosy.

In addition, group meetings were organised in the villages to obtain a collective opinion of the community about the disease and its socio-cultural correlates. However, the main purpose that these meetings served was to help establish our presence in the village and to convey to the community as a whole the purpose of our study so that we would get adequate cooperation. In these meetings it was difficult to avoid discussion on local problems, which were invariably other than leprosy or health issues.

Interviews of leprosy technicians and other health staff were also conducted to get an understanding into the functioning of the National Leprosy Control Program. Extracts from these meetings are reproduced in Appendix B.

DATA ANALYSIS

The data gathered through structured interviews was processed in a computer and the SPSS program was used to obtain tables for analysis.

All the data of the study are presented as a dichotomous division into high and low endemic areas and therefore the analysis will focus at locating differentials between the two areas besides a general overall analysis. The reason for this is that we began with the hypothesis that social stigma against leprosy is greater in the low endemic areas because of the secrecy associated with it in these areas, whereas; because of wide prevalence, in the high endemic areas, the stigma should be less severe, if not absent.

For the high endemic area sample we will also make an analysis for selected variables to bring out any differences due to NGO intervention (in this case the GMLF). This will not be done for the low endemic area sample because the NGOs studied in those areas have not put in any special efforts at dealing with any aspect of leprosy.

The main dependent variables that will be analysed are "knowledge of leprosy", "whether will allow leprosy patient to enter in the house", "whether will work with leprosy patient" and "reasons for the stigma".

SECTION TWO : LEPROSY AND SOCIETY

3. ABOUT THE PEOPLE AND AREA

Differentials Among Sample Households and Population

Endemicity of Leprosy

Stratification

Occupation

Education

NGO Intervention

Social Geography of the Study area

Map of Maharashtra showing study areas

4. ABOUT WHAT PEOPLE KNOW

5. ABOUT HOW PEOPLE FEEL AND ACT

ABOUT THE PEOPLE AND AREA

Findings pertaining to the characteristics of the sample households and population and description of the study area.

The households and population that comprise the sample of the study are differentiated on the basis of certain characteristics that may (or may not) be crucial to the results of the study. These differentiating characteristics include endemicity of leprosy in the population, stratification (caste and landholding), education and involvement of a non-government organisation.

DIFFERENTIALS AMONG SAMPLE HOUSEHOLDS AND POPULATION

Endemicity of Leprosy : The sample households comprise two major groups. One group is those households that are located in regions having low leprosy endemicity - prevalence rate of less than 3 per 1000 population. The second group is that of high endemicity population - prevalence rate of greater than 7 per 1000 population. For the low endemic area our sample was 711 households spread over 18 villages in 4 districts of Maharashtra, and for the high endemic area the sample was 95 households spread over 4 villages from 2 districts of Maharashtra. The endemicity (prevalence rate) in the districts and our findings in the sample villages are given in Table 3.1. In our sample area the prevalence rates in the high and low endemic areas were 14.68 and 1.6 per 1000 population, respectively.

Table 3.1 : PREVALENCE OF LEPROSY IN THE STUDY DISTRICTS AND SAMPLE POPULATION (PER 1000 POPULATION)

	PREVALENCE RATE AS PER 1981 CENSUS	PREVALENCE * RATE AS PER FINDINGS IN STUDY SAMPLE
HIGH ENDEMIC AREA		
1. Brahmapuri LCU area of Chandrapur District	19.33	22.05
2. Sewagram LCU area of Wardha District	7.95	6.30
LOW ENDEMIC AREA		
3. Aurangabad district	2.84	2.11
4. Pune district	2.24	1.93
5. Dhule district	2.50	1.09
6. Ratnagiri district	1.78	0.94

* : Prevalence based on registered active cases through state health services for estimated population of 1985.

The high endemic areas have Leprosy Control Units (LCU) that generally coincide with a taluka area. In the low endemic areas the Leprosy Control Program operates through the Primary Health Centres with the aid of a leprosy technician. The Brahmapuri LCU run by the government health services has one of the highest prevalence rates in the state whereas the Sewagram LCU area run by a non-government agency (Gandhi Memorial Leprosy Foundation) has over the years reduced the prevalence rate through their intensive work.

Stratification : The **two areas have a distinctly different caste/community distribution** of the population. The high endemic areas have a numeric dominance of "lower" castes whereas the low endemic areas have a predominance of "upper" castes. It may be noted that generally caste and economic status have a direct relationship. Table 3.2 gives the castewise distribution of the sample households in the two areas.

Table 3.2 : CASTE/COMMUNITY DISTRIBUTION OF SAMPLE HOUSEHOLDS (PERCENTAGES)

	HIGH ENDEMIC AREA	LOW ENDEMIC AREA	COMBINED AREA**
Upper caste * Hindus	3.16	42.48	37.84
Lower caste Hindus	50.53	19.97	23.57
Scheduled Caste	25.26	11.54	13.15
Scheduled Tribes	20.00	18.00	18.24
Muslims	1.05	8.01	7.20
All Communities	100.00 (N=95)	100.00 (N=711)	100.00 (N=806)

* : Brahmins and Marathas
$X^2 = 85.27$; 4df; highly significant
** : weighted

With regard to **landholding status** too the **populations in the high and low endemic areas differ significantly**. The proportion of the marginal and small peasants and the rich peasants in the sample population is similar in the high and low endemic areas but the rest is different. In the high endemic area the landless is significantly a larger proportion whereas in the low endemic areas the middle peasant is larger. This difference accounts for the significant chisquare value as shown in table 3.3.

Table 3.3 : LANDHOLDING DISTRIBUTION OF THE SAMPLE HOUSEHOLDS (PERCENTAGES)

	LANDLESS	MARGINAL & SMALL PEASANTS (upto 5 acres)	MIDDLE PEASANTS (upto 20 acres)	RICH PEASANTS (more than 20 acres)	ALL CLASSES
High Endemic Area	33.68	44.21	18.95	3.16	100.00 (N=95)
Low Endemic Area	20.25	45.71	29.96	4.08	100.00 (N=711)
Combined Area	21.84	45.53	28.66	3.97	100.00 (N=806)

X^2 = 10.69; 3df; highly significant.

While crosstabulating community and landholding for both the areas it is revealed that there is no significant differential pattern of these two variables in the high endemic area mainly because of underrepresentation of "upper" castes in the sample, but in the low endemic area the difference is highly significant (X^2 = 120.5 for 12 df) indicating a high concentration of land holding in the hands of the "upper" castes. (Table 3.4) Thus in the low endemic area the **"upper" castes who constitute 42% of the households own 55% of the agricultural land (Mean landholding of 8.2 acres) and only 10% of the** "upper" castes are landless. Whereas the scheduled castes and tribes in the low endemic area own only 6% and 12% of the land (mean landholding of 3.4 acres and 4.1 acres) when they constitute 12% and 18%, respectively, of the households; **and half of the scheduled caste and 27% of scheduled tribe households are landless.** In the high endemic area there is more or less equity in amount of land held by a community to its proportion in the poopulation. This, as stated earlier, is possibly due to traditional "upper" castes being an insignificant proportion of the population, as also due to the fact that the sample high endemic areas are agriculturally poor productivity areas when compared to the sample low endemic areas.

Table 3.4 : LANDHOLDING BY COMMUNITY (NUMBER OF HOUSEHOLDS)

LANDHOLDING	COMMUNITY					
	HIGH CASTE HINDUS	LOW CASTE HINDUS	SC	ST	MUSLIMS	ALL CLASSES
HIGH ENDEMIC						
Landless	0	15	7	9	0	31
Small & Marginal Peasants	2	21	11	8	0	42
Middle Peasants	1	9	5	2	1	18
Rich Peasants	0	2	2	0	0	4
All Classes	3	47	25	19	1	95
Mean Landholding in acres(Std.error)	6(3.5)	4.9(1.03)	6.1(1.7)	2.4(0.9)	13(0)	4.8(0.7)
X^2 = 9.89; 12 df. not significant.						
LOW ENDEMIC						
Landless	30	30	41	35	8	142
Small & Marginal Peasants	128	84	26	68	19	325
Middle Peasants	128	25	14	23	23	213
Rich Peasants	16	3	1	2	7	29
All Classes	302	142	82	128	57	711
Mean Landholding in acres(Std.error)	8.2(0.4)	4.4(0.48)	3.38(0.6)	4.1(0.48)	9.7(1.2)	6.26(0.26)
X^2 = 120.54; 12 df. Highly significant.						

Occupation : Occupationwise distribution of the respondents for both the areas follows the same pattern as that seen with regard to the landholding of the households. For land is still the primary productive asset in the rural areas. Higher proportion of the landless and marginal farmers households in the high endemic area is reflected in the occupational structure of the respondents - 42% of them are landless labourers-cum-manual workers. In the low endemic area this category of occupation accounts for only 17.3 of respondents as there is preponderance of middle and marginal farmers in the sample. As a result, the occupation-wise distribution shows highly significant difference between both the areas. (Table 3.5)

Table 3.5 : OCCUPATION DISTRIBUTION OF RESPONDENT (PERCENTAGES)

OCCUPATION	HIGH ENDEMIC AREA	LOW ENDEMIC AREA	COMBINED AREA
Non-workers, including student, housewife	5.3	1.8	2.2
Paid Domestic Worker	4.2	0.0	0.5
Paid Agricultural Worker-cum-Mol Mazdoori	42.0	17.3	20.2
Cultivator-cum-Worker	20.0	26.6	25.8
Cultivator only	19.0	35.3	33.4
Artisan	2.1	2.5	2.5
Self-employed Petty trader	2.1	5.1	4.7
Others	5.3	11.4	10.7
All Occupations	100 (N=95)	100 (N=711)	100 (N=806)

X^2 = 72.55, 7df. highly significant

Education: With regard to education the respondents in the two areas are not significantly different as seen in Table 3.6

Table 3.6 : EDUCATION ACHIEVEMENT OF RESPONDENTS (PERCENTAGES)

AREA	NIL	UPTO 7th	SECONDARY & HIGHER	TOTAL
High Endemic	49.5	36.8	13.7	100(N=96)
Low Endemic	57.1	35.1	7.8	100(N=706)

X^2 = 4.36; 2df. not significant.

However, in relation to landholding and community, it is important to note that education is an important variable because access to it is determined to a fair extent by these two factors. Table 3.6 shows the correlation of education with these two variables.

It is clear from Table 3.7 that in the low endemic areas education is significantly related to Landholding and Community. **Education opportunities are largely cornered by those from landed classes and those from among dominant castes**. However, in the high endemic areas, though the trend is similar, the relationship of these variables is not statistically significant. The distribution pattern is similar to the relationship between landholding and community and the same reasons discussed in an earlier section hold in this case too. Thus, the landless and oppressed communities have a higher proportion of respondents who never enrolled in schools.

NGO Intervention : Another important differentrating characteristic in the sample is that in both the high and low endemic areas the households have been sampled in two segments, one group in each area being a set of households that had access to benefits from a non-government organisation (NGO) and the other group being a set of households with no such intervention (the rationale behind this has been explained in the section on methodology). In the low endemic area all the NGOs were those who did general health and development work but in the high endemic area the NGO covered is one that is doing work specifically in the field of leprosy. This difference between the two areas is important because on the whole "NGO intervetion" as a variable will not be considered for analysis in this report because in the low endemic area it doesn't play any significant role where

Table 3.7 : EDUCATION LEVEL OF RESPONDENTS BY LANDHOLDING & COMMUNITY

characteristics	EDUCATION LEVEL OF RESPONDENTS (Percentage) LOW ENDEMIC AREA nil	upto 7th	secondary & higher	total	HIGH ENDEMIC AREA nil	upto 7th	secondary & higher	total
Landholding								
Landless	70	28	2	100 (N=143)	55	35	10	100 (N=31)
Marginal & small peasants	59	35	6	100 (N=323)	48	36	16	100 (N=42)
Middle Peasants	47	41	12	100 (N=211)	50	33	17	100 (N=48)
Rich Peasants	45	34	21	100 (N=29)	25	75	0	100 (N=4)
	X^2 = 32.54; 6df. highly significant				X^2 = 3.67; 6df. not significant			
Community								
Upper Caste	44	45	11	100 (N=299)	34	33	33	100 (N=3)
Low Caste	56	38	6	100 (N=144)	40	47	17	100 (N=47)
Scheduled castes	70	26	4	100 (N=80)	44	44	12	100 (N25)
Scheduled tribes	73	24	3	100 (N=126)	79	16	5	100 (N=19)
Muslims	74	14	12	100 (N=57)	100	0	0	100 (N=1)
	X^2 = 52.15; 8df. highly significant				X^2 = 10.77; 8df. not significant			

parameters for "social aspects of leprosy" (the theme of the present study) are concerned. However, a separate section on role of NGO intervention in the high endemic area will look into the significance of this issue. (See Appendix A)

Social Geography Of The Study Area

The low endemic study sample was spread across 18 villages of 4 districts (Ratnagiri, Dhule, Aurangabad and Pune) and the high endemic sample was from 4 villages, two each in Wardha and Chandrapur districts. A brief profile of these districts is presented in the following paragraphs.

Ratnagiri District is part of coastal Maharashtra. Its unique features include high out-migration, a high feminity sex-ratio and a majority of female-headed households. Ratnagiri is extremely backward, though very rich in natural resources. It is a single crop area (monsoon). Almost every rural household has atleast one person working in large cities such as Bombay, Pune and Kolhapur.

Dhule District is predominantly a tribal area and is also backward. However some irrigation is available enabling the cultivation of cotton as a cash crop over and above their staple food crop. The forests have gradually disappeared to make way for cultivation since pressure on land has increased as non-tribals increasingly acquire a larger share of the local economy.

Aurangabad District is in central Maharashtra. It is a fast developing area. Aurangabad city and its periphery is at present probably the fastest industrialising area is Maharashtra. The Jaikwadi dam in Paithan (though benefiting Nanded district more than Aurangabad) has made possible the enhancing of agricultural production. It is an area in transition, but highly stratified with caste and community groups getting increasingly polarised and in constant conflict with one another.

Pune District is a developed area. Industrial and agricultural development is good and the peasantry is organised: over 47% of the population is urban and more than half the population is literate.

Wardha District is associated with Gandhian values. This district has a number of Gandhian institution, many of whom are involved in Leprosy related work. It is a fairly backward

district with 48% of the workforce comprising of agricultural labourers. However it has a high literacy rate (51%) and a low population growth rate (1.88%)

Chandrapur District is the largest and most backward district of Maharashtra. Its one segment (now Gadchiroli district) is predominantly tribal. The literacy rate is only 35% and only 13% of the population lives in urban areas. Chandrapur also has the highest Leprosy prevalence rate in the state (12.23 per 1000 population in 1981).

DHULE
AURANGABAD
WARDHA
CHANDRAPUR
PUNE
RATNAGIRI
MAHARASHTRA STATE
STUDY AREA

ABOUT WHAT PEOPLE KNOW (OR WHAT THEY TOLD US ABOUT LEPROSY)

As explained in the section on Methodology, there was some difference in the questions asked to the respondents in the high and low endemic areas.

With regard to **knowledge of leprosy**, two sets of questions were asked (1) whether they know anyone suffering from leprosy and (2) whether they know anything about the disease? If the answer to the second question was affirmative then, they were questioned about what they knew of the disease -no clues were given. For the high endemic area population, we presumed that they would know leprosy patients because of the high prevalence; therefore this question was considered redundant and respondents were only asked about their knowledge of the disease. Additionally they were asked how they acquired this knowledge and how serious they regarded the disease to be.

In the low endemic area 84.6% of the respondents had never seen a leprosy patient and 60.88% had no knowledge about leprosy. In the high endemic area only 14.74% of the respondents did not have any knowledge about leprosy. (see table 4.1).

Table 4.1 : KNOWLEDGE ABOUT LEPROSY (PERCENTAGES)

WHETHER KNOW	LOW ENDEMIC AREA		HIGH ENDEMIC AREA
	KNOWLEDGE ABOUT LEPROSY PATIENTS	KNOWLEDGE ABOUT LEPROSY	KNOWLEDGE ABOUT LEPROSY
YES	15.4	39.1	85.3
NO	84.6	60.9	14.7
TOTAL	100.0 (N=708)	100.0 (N=703)	100.0 (N= 95)

X^2 value (between knowledge of leprosy & endemicity) = 72.12; 1df, highly significant.

It is clear from Table 4.1 that **prevalence of the disease is to a large extent responsible for the respondents knowledge about**

the disease. If people do not get to see patients suffering from the disease the chances are they would not even know about its existence. Since leprosy is mainly associated with its deformity the chance of finding a deformed patient in a low endemic area is very marginal. On the other hand in a high endemic area a deformed leprosy patient is a fairly common sight and comes easily to the notice of the population.

Table 4.2 : SELECTED RESPONDENT CHARACTERISTICS & KNOWLEDGE OF LEPROSY

RESPONDENTS CHARACTERISTICS	KNOWLEDGE OF LEPROSY (percentages) HIGH ENDEMIC AREA YES	NO	TOTAL	LOW ENDEMIC AREA YES	No	TOTAL
A. LAND HOLDING						
Landless	87	13	100	43	57	100
Marginal & small	81	19	100	36	64	100
Middle	100	0	100	38	62	100
Rich	50	50	100	55	45	100
X^2= 7.77; 3df. not significant				X^2= 5.32; 3df. not significant		
B. COMMUNITY						
High castes	100	0	100	41	59	100
Low castes	87	13	100	34	66	100
scheduled castes	83	17	100	35	65	100
Scheduled tribes	79	21	100	32	68	100
Muslims	100	0	100	63	37	100
X^2= 1.56; 4df. not significant				X^2= 19.29; 4df.hig.significant		
C. EDUCATION						
No schooling	79	21	100	36	64	100
Upto middle school	89	11	100	39	61	100
Secondary & Higher	100	0	100	64	36	100
X^2= 4.15; 2df. not significant				X^2= 15.62; 2df.hig.significant		
	N=81	N=14	N=95	N=275	N=428	N=703

Do other factors such as **socio-economic status** influence knowledge about the disease? Table 4.2 presents distribution of respondents with regard to their knowledge about leprosy in relation to three socio-economic variables: landholding (economic status), community (social status) and education. It may be noted that these three variables are not independent of each other. As shown in the preceding chapter high economic status, social status and educational achievement go together.

Thus we see in Table 4.2 that in low endemic areas where knowledge of leprosy is "low" among the population these status factors are important especially community, and educational achievement. A larger proportion of respondents of "higher" or dominant castes, due to their better social and economic placement, have knowledge about leprosy. Similarly those with larger landholding and higher education have a larger proportion of households having knowledge of leprosy. In low endemic areas the knowledge of leprosy is acquired more through cultural means than through actual exposure to or experience of the disease. And the chances are that a lot of myth gets included in this cultural transmission. This is evident from the type of knowledge of leprosy reported by respondents from low endemic areas. (see Table 4.3).

In the high endemic areas these socio-economic factors are not statistically significant because the high prevalence rate of leprosy and the high profile of the leprosy program, makes knowledge of leprosy cut across these factors. Nevertheless the percentage distributions of the high endemic areas show that the trend is similar to the significant distributions of the low endemic areas. Also, we have seen in Chapter 3 that Caste and Landholding differences are very marginal in the high endemic area. Therefore we expect non-significant variation between classes in the high endemic area, unlike the low endemic area where variation is wide.

Further, as expected, the type or content of knowledge reported by respondents in the high and low endemic areas is significantly different. (See Table 4.3)

Table 4.3 : CONTENT OF KNOWLEDGE OF LEPROSY

(FOR THOSE REPORTING AS HAVING KNOWLEDGE) (percentage)

CONTENT OF KNOWLEDGE	LOW ENDEMIC AREA	HIGH ENDEMIC AREA
Correct	69	84
Partially correct or incorrect	31	16
	100 (N=275)	100 (N=81)

$X^2 = 6.92$; 1df. highly significant

In the high endemic area a significantly larger proportion of the respondents reported having correct knowledge as compared to low endemic areas. Correct knowledge refers to a symptomatically correct (to the extent of 75%) response. Such responses include "anaesthetic patch", "body loses sensation", "flattening and swelling of nose and/or ear", "loss of eyebrows", "loss of extremities", "stiffening of finger joints" "ulceration and unhealing wounds", "changes in look of face". Incorrect responses include "skin becomes completely white" "Leprosy contracted if you eat pork" "contracted due to nutritional deficiencies" "Rash on skin", "Red patches on body".

It must be noted that our classification of responses as "correct" and "incorrect" may be questioned. But it should be kept in mind that the above responses were obtained in specific reference to leprosy; and also the translation of local words used for various signs and symptoms may not be very precise.

Again the high prevalence of leprosy and an active leprosy control program in the high endemic area is largely responsible for a significantly larger proportion of respondents reporting "correct" knowledge. Socio-economic factors in this case are statistically not significant, either in the high or low endemic areas. (see Table 4.4) However, the distribution in Table 4.4 shows an interesting (though not statistically significant) trend-the respondents of oppressed classes (landless, scheduled castes) constitute a larger percentage of those with "correct" knowledge in both high & low endemic areas; and with regard to education more respondents with a higher level of education reported "correct" knowledge. This possibly indicates that the dominant groups (community or landholdingwise), who have a vested interest in maintaining exploitative traditions, are more likely to transmit myths about the disease than the oppressed who learn more from their direct experiences.

It is clear from the foregoing discussion that there is a significant difference in both knowledge and content of knowledge of leprosy between high and low endemic areas ; and that in low endemic areas where knowledge is not widespread, and is largely transmitted through culture and not from actual experience, there is a significant role played by socio-economic factors in determining knowledge. Also, the wider variation between various classes in low endemic areas is an important contributing factor to wider differences between classes with regard to knowledge of

Table 4.4 : CONTENT OF KNOWLEDGE OF LEPROSY BY LANDHOLDING COMMUNITY, AND EDUCATION OF RESPONDENTS

(CONTENT OF KNOWLEDGE OF LEPROSY) (Percentage)

CHARACTERISTICS	LOW ENDEMIC AREA			HIGH ENDEMIC AREA		
	CORRECT	PARTIALLY CORRECT AND/OR INCORRECT	TOTAL	CORRECT	PARTIALLY CORRECT AND/OR INCORRECT	TOTAL
Landholding						
Landless	79	21	100 (N=62)	85	15	100 (N=27)
Marginal & Small peasants	65	35	100 (N=117)	79	21	100 (N=34)
Middle peasants	67	33	100 (N=80)	83	17	100 (N=18)
Rich peasants	69	31	100 (N=16)	100	0	100 (N=2)
	X^2 = 3.9; 3df. not significant			X^2 = 0.94; 3df. not significant		
Community						
High castes	63	37	100 (N=123)	67	33	100 (N=3)
Low castes	65	35	100 (N=49)	83	17	100 (N=42)
Scheduled castes	89	11	100 (N=27)	95	5	100 (N=20)
Scheduled tribes	70	30	100 (N=40)	73	27	100 (N=15)
Muslims	78	22	100 (N=36)	100	0	100 (N=1)
	X^2 = 8.08; 4df. not significant			X^2 = 3.9; 4df. not significant		
Education						
NIL	64	36	100 (N=144)	76	24	100 (N=37)
Upto 7th	74	26	100 (N=96)	87	13	100 (N=31)
Secondary and Higher	77	23	100 (N=35)	100	0	100 (N=13)
	X^2 = 3.95; 2df. not significant			X^2 = 4.59; 2df. not singificant		
N of cases	190	85	275	68	13	81

leprosy. This clearly indicates that class differences are important factors and are significantly responsible for differences, if any, among the study variables.

In the high endemic areas an additional question about **how knowledge of leprosy was acquired** was asked (in the low endemic area we obtained this information through group interviews and meetings). Table 4.5 show that 96% of the respondents acquired the knowledge through self observation and experience. As stated earlier this factor is largely responsible for larger proportion of respondents in high endemic area reporting "correct" knowledge.

Table 4.5 : HOW KNOWLEDGE OF LEPROSY ACQUIRED?

KNOWLEDGE ACQUIRED	PERCENTAGE RESPONDENTS
1. Through Cultural Transmission	2.5
2. Through Doctors & paramedicals	1.5
3. Through self observation/experience	96.0
Total	100.0 N=81

In the high endemic area we also enquired from respondents as to how serious a disease they regarded leprosy to be **(what care a leprosy patient should take?)** Table 4.6 shows that 70% of the respondents said that leprosy patients required a long term (atleast 3 years) uninterrupted treatment, and 30% said that they needed special attention and isolation.

Table 4.6 : WHAT CARE A LEPROSY PATIENT SHOULD TAKE

WHAT CARE	PERCENTAGE OF RESPONDENT
1. Need special attention & isolation	29.6
2. Take long term treatment	70.4
ALL	100.0 (N=81)

Tables 4.5 and 4.6 strengthen's the findings of Table 4.3 and is a possible indicator of the fact that the education component of the leprosy program has had some impact, and also that stigma towards leprosy may be lower in the high endemic area. The subsequent chapters deal with this issue.

ABOUT HOW PEOPLE FEEL AND ACT (OR WHY THEY DONT LIKE LEPROSY)

As discussed in the section on `Methodology´ two aspects pertaining to stigma of leprosy were investigated. One, whether people allow leprosy patients to enter their houses, and second, whether they allow leprosy patients to work with them. These two questions were asked only to respondents who affirmed having knowledge of leprosy. Those who said that they would not allow leprosy patients to enter and/or would not allow them to work with themselves were asked to give reasons.

The reasons were recorded as reported by respondents and have been classified later on into categories for the purpose of analysis.

In the chapter on `Methodology´ we have stated that we began with the hypothesis that there is a difference in stigma in low and high endemic areas - that stigma is significantly lower, if not absent, in the high endemic areas.

We have put to test the hypothesis in terms of the two questions stated above. On both counts the hypothesis has been disproved and we have to accept the hypothesis of no difference because of the extremely insignificant X^2 values. (Table 5.1)

Table 5.1 : WHETHER ALLOWS LEPROSY PATIENTS TO ENTER HOUSE AND TO WORK WITH

ENTRY INTO HOUSE (percent)		
ALLOW TO ENTER	LOW ENDEMIC	HIGH ENDEMIC
YES	17	19
NO	83	81
TOTAL	100 (N=258)	100 (N=81)
X^2 val. 0.092; 1df. not sig.		

ALLOWING TO WORK WITH (Percent)		
ALLOW TO WORK	LOW ENDEMIC	HIGH ENDEMIC
YES	16	15
NO	84	5
TOTAL	100 (N=258)	100 (N=81)
X^2 val. 0.02; 1df. not sig.		

Table 5.2 : RESPONDENT CHARACTERISTICS BY ENTRY INTO HOUSE AND ALLOWING TO WORK WITH

(Percentage)

CHARACTERISTICS	ENTRY INTO HOUSE						ALLOWING TO WORK WITH					
	LOW ENDEMIC AREA			HIGH ENDEMIC AREA			LOW ENDEMIC AREA			HIGH ENDEMIC AREA		
	YES	NO	TOTAL	YES	NO	TOTAL	YES	NO	TOTAL	YES	NO	TOTAL
A. LANDHOLDING												
Landless	15	85	100 (N=61)	22	78	100 (N=27)	16	84	100 (N=61)	19	81	100 (N=27)
Marginal and small peasant	18	82	100 (N=106)	15	85	100 (N=34)	16	84	100 (N=106)	9	91	100 (N=34)
Middle peasant	17	83	100 (N=78)	22	76	100 (N=18)	13	87	100 (N=78)	22	78	100 (N=18)
Rich peasant	23	77	100 (N=13)	0	100	100 (N=2)	23	77	100 (N=13)	0	100	100 (N=2)
X^2 Value	0.63; 3df; not significant			1.06; 3df; not significant			1.06; edf; not significant			2.39; 3df; not significant		
B. COMMUNITY												
Upper caste	20	80	100 (N=116)	33	67	100 (N=3)	16	84	100 (N=116)	33	67	100 (N=3)
Lower caste	12	88	100 (N=41)	24	76	100 (N=42)	15	85	100 (N=41)	27	83	100 (N=42)
Scheduled castes	23	77	100 (N=26)	15	85	100 (N=20)	19	81	100 (N=26)	15	85	100 (N=20)
Scheduled tribes	5	95	100 (N=41)	7	93	100 (N=15)	10	90	100 (N=41)	7	93	100 (N=15)
Muslims	24	76	100 (N=34)	0	100	100 (N=1)	21	79	100 (N=34)	0	100	100 (N=1)
X^2 Value	7.29; 4df; not significant			3.0; 4df; not significant			1.52; 4df; not significant			1.89; 4df; not significant		
C. EDUCATION												
NIL	16	84	100 (N=128)	22	78	100 (N=37)	13	87	100 (N=128)	19	81	100 (N=37)
Upto 7th	16	84	100 (N=88)	16	84	100 (N=31)	16	84	100 (N=88)	13	87	100 (N=31)
Secondary & higher	40	60	100 (N=20)	15	85	100 (N=13)	21	79	100 (N=34)	8	92	100 (N=13)
X^2 Value	6.96; 2df; significant			0.44; 2df; not significant			1.16; 2df; not significant			1.11; 2df; not significant		
D. OCCUPATION												
Non-worker including student & housewife	17	83	100 (N=6)	50	50	100 (N=4)	17	83	100 (N=6)	50	50	100 (N=4)
Paid Domestic Worker	0	0	0	50	50	100 (N=4)	0	0	0	50	50	100 (N=4)
Paid Agricultural Worker-cum-Mol Mazdoori	18	82	100 (N=39)	18	82	100 (N=34)	21	79	100 (N=39)	12	88	100 (N=34)
Cultivator-cum-Worker	20	80	100 (N=83)	18	82	100 (N=17)	11	89	100 (N=83)	18	82	100 (N=17)
Cultivator only	17	83	100 (N=78)	7	93	100 (N=15)	18	82	100 (N=78)	7	93	100 (N=15)
Artisan	14	86	100 (N=7)	0	100	100 (N=2)	0	100	100 (N=7)	0	100	100 (N=2)
Self-employed Petty Trader	14	86	100 (N=22)	0	100	100 (N=2)	14	86	100 (N=22)	0	100	100 (N=2)
Others	17	83	100 (N=23)	20	80	100 (N=5)	22	78	100 (N=23)	0	100	100 (N=5)
X^2 Value	2.31; 6df; not significant			7.73; 2df; not significant			4.51; 6df; not significant			10.77; 7df; not significant		

Tables 5.1 and 5.2 provide clear evidence that the sample respondents in the high and low endemic areas have similar attitudes or feelings towards leprosy patients. The percentage of respondents in both areas who have expressed feelings of unwillingness to closely interact with leprosy patients is as high as 82.59% (entry into house) and 84.46% (willingness to work with), and the variation between the high and low endemic areas is negligible. Distribution of responses in each category is almost identical.

Do socio-economic background differences, which as we have seen earlier are statistically significant differentials between the two areas, matter in their willingness or unwillingness to interact with leprosy patients?

We had anticipated the oppressed classes - classes which themselves are stigmatised - to have less stigma of leprosy as compared to others, firstly because the social structure places them in a stigmatised situation (the scheduled castes for instance), and secondly because of their position they don't have much of a choice.

The distribution in Table 5.2 shows that socio-economic factors too don't matter in determining stigma, at least statistically. The hypothesis of no difference with regard to stigma of leprosy still holds good. We have seen in the preceding chapter that endemicity of leprosy plays a highly significant role in determining knowledge, as well as content of knowledge of leprosy; and some significant relationship with socio-economic variables, especially in low endemic areas, also exist.

For instance in high endemic areas where knowledge is significantly better and the proportion of respondents reporting "correct" knowledge is significantly higher than low endemic areas, and where knowledge has been acquired mainly from self observation & experience of respondents, one would expect a more "rational" attitude towards leprosy. But the data clearly shows that inspite of this difference in comparison with low endemic areas, the respondents of high endemic areas harbour an equal "amount" of stigma as well as share more or less similar reasons (see Table 5.3) for the stigma of leprosy.

Thus we see that these differentials are not important, except education in low endemic areas (which is questionable because the same educated respondents who were willing to let leprosy patients enter their house were unwilling to work with them). **This means that stigma towards leprosy is universal, and independent (atleast statistically) of the factors that we have discussed.**

What are the **reasons for this stigma?** A series of reasons were given to us by respondents. We have categorised these reasons into classes, which possibly have some overlap. However, we have listed out the range of responses for each class also. Table 5.3 gives the distribution of respondents by reason for their stigma of leprosy patients.

Table 5.3 : REASONS FOR NOT ALLOWING LEPROSY PATIENTS TO ENTER HOUSE AND FOR NOT WILLING TO WORK WITH THEM

REASON FOR NON-ENTRY			(PERCENTAGE) REASON FOR NOT WILLING TO WORK WITH	
REASON	LOW ENDEMIC	HIGH ENDEMIC	LOW ENDEMIC	HIGH ENDEMIC
Patients stay away	7.9	0.0	13.3	1.4
Fear of contracting leprosy	76.2	77.3	71.1	82.6
Fear of ostracism	8.9	16.6	6.9	11.6
Other	7.0	6.1	8.7	4.4
TOTAL	100 (N=214)	100 (N=66)	100 (N=218)	100 (N=69)

What do these reasons mean?

Patients stay away means that they themselves are unwilling to interact with the respondents for whatever reasons.

Fear of Contracting Leprosy includes reasons like "because it is communicable", "we are scared of leprosy", "close contact can give us leprosy", "skin or breath or urine contact of patient can cause leprosy".

Fear of Ostracism includes reasons such as "will lose social respectability", "Will get associated as having leprosy", "Society has ostracised them", "if we associate we may be ostracised".

Others includes reasons as "they smell horrible", "they are dirty", "they are sinners", "urine and spit of leprosy patients is harmful", "they have repulsive looks".

It is then clear from this discussion that the stigma of leprosy is deep seated in society. It is an organic part of the social structure and cuts across classes, socially and culturally differentiated groups etc.

The question that arises now is why does this stigma prevail? What are the issues related to it that makes its elimination difficult? In the introduction we have raised these questions and placed them in the context of a stigmatised society whose oppressive and exploitative nature has provided a basis for various stigmas. Leprosy is only one, probably the most vile because of the necrosis associated with it. And the stigma of leprosy is not independent of other stigma within society. They are all interrelated and emerge, we contend, from the nature of the social structure itself.

SECTION THREE : PATIENT AND SOCIETY

6. A NOTE ON NON-RESPONSE IN PATIENT INTERVIEWS

Profile of Non-Responders

7. SOCIAL BACKGROUND OF THE PATIENT

Age, Sex and Marital Status

Community, Education and Landholding

8 PATIENT'S DISEASE PROFILE

Onset of Leprosy

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Deformity and the Patient

9. PATIENTS INTERFACE WITH SOCIETY

10. INFORMAL INTERVIEWS OF SELECTED PATIENTS

THE LEPROSY PATIENT
NOTE ON NON-RESPONSE IN PATIENT INTERVIEWS.

In this section we describe the results of the study based on leprosy patient interviews. It is a description of a leprosy patient's experience after s/he has got the disease. Interviewing leprosy patients was not easy and we have encountered a high non-response rate to various questions in interviewing patients. As stated earlier in the chapter on "Methodology" we had to be very cautious in dealing with the patients because affliction of leprosy places the patient in a very sensitive situation.

Before we proceed further, a note on non-response is necessary. Unlike household interviews, we encountered a high rate of non-response for various questions when patients were interviewed. On an average in the high endemic area 17% and in the low endemic are 11% of the patients refused to respond to various questions pertaining to their experiences regarding treatment of the disease as well as to questions about their interaction with society. In the following chapters each table mentions the percent of non-responders. Below we present a brief profile of the non-responders in our sample.(Table 6.1)

Table 6.1 : NON - RESPONSE RATE

CHARACTERISTIC	HIGH ENDEMIC AREA (N=12 OUT OF 70)		LOW ENDEMIC AREA (N=4 OUT OF 35)	
	Number	Category %	Number	Category%
Landholding				
Landless	3	17	1	7
Marginal & Small peasants	4	11	1	13
Middle and Rich Peasants	5	36	2	17
Caste				
Upper caste	-	-	4	24
Lower caste	6	18	-	-
Scheduled caste	4	19	-	-
Scheduled tribe	2	13	-	-
Sex				
Male	8	20	2	8
Female	4	14	2	18
Age				
Under 20	8	42	-	-
20-39	3	13	-	-
40+	1	4	4	15
Education				
No schools	3	8	4	17
Upto 7th	7	32	-	-
Secondary & higher	2	25	-	-

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Profile of Non-Responders

The patients from middle and rich peasant class in both the areas, the upper caste patients in low endemic area, patients under 20 in high endemic area and patients over 40 in low endemic areas, and those who have had a school education in high endemic areas have a majority of the non-responders - both in terms of absolute numbers as well as a percentage of their own class.

We crosstabulated and correlated the non-response rate for each class of the "landholding", "caste" and"education" variables with the prevalence rate of leprosy for that class. Interestingly we obtain relatively significant negative correlation, especially in the case of landholding and education. (Table 6.2).

Table 6.2 : CORRELATION BETWEEN NON-RESPONSE & LEPROSY PREVALENCE RATE

	HIGH ENDEMIC AREA		LOW ENDEMIC AREA	
	Non-response Rate (%)	Prevalence Rate (per 1000)	Non-response Rate (%)	Prevalence Rate (per 1000)
LANDHOLDING				
Landless	17	11.44	7	3.20
Marginal & small Peasants	11	17.87	13	0.82
Middle & Rich Peasants	36	13.10	17	1.66
Pearsons r	-0.48		-0.72	
COMMUNITY				
Upper caste	-	-	24	1.88
Lower caste	18	13.73	-	-
Scheduled caste	19	17.41	-	-
Scheduled tribe	13	16.77	-	-
Pearsons r	-0.20		--	
EDUCATION				
No schooling	8	16.94	4	1.97
Upto 7th	32	12.54	-	-
Secondary & Higher	25	12.23	-	-
Pearsons r	-0.94		--	

This means higher the prevalence rate among a category of population the lower was the non-response rate in our sample. This possibly indicates that low prevalence of leprosy in a given population may have acted as a barrier to response among the patients with regard to questions about treatment and change in attitudes towards the patient after s/he got leprosy.

7

SOCIAL BACKGROUND OF THE PATIENT

This chapter describes socio-economic characteristics of leprosy patients in the high and low endemic areas. Please note that the leprosy patients included in the sample are all the registered (currently active on the register) cases at the PHC or LCU from the villages included in the study. The differences (if any) that have been highlighted (age-sex structure, community, landholding, education) should not be used to reach a conclusion that these differentiating characteristics directly influence endemicity or the occurance pattern or visa versa. The reason for highlighting these differences is merely to indicate that these differences exist and that they may be important in the determination of stigma in general, and in attitudes towards the patients in particular, as well as in the patients' interface with society.

Age, Sex and Marital Status

The pattern of age-distribution of patients in the high and low endemic areas is significantly different. In the high endemic sample patients range across a wide age-spectrum, but in the low endemic area they are concentrated in higher age groups. The mean age of a leprosy patient in the high endemic area is 33.6 years and in the low endemic area 44.6 years.

The difference of the age pattern is reflected in the highly significant X^2 value (see Table 7.1). This is understandable because a higher prevalence rate is bound to infect a wider spectrum of population. Table 7.1 indicates the age difference between the two patient populations.

Table 7.1 : AGE DISTRIBUTION OF LEPROSY PATIENTS (Percent)

AGE GROUP (YEARS)	HIGH ENDEMIC PATIENTS	LOW ENDEMIC PATIENTS
Below 20	27.1	5.7
20 - 39	34.3	17.1
40 and above	38.6	77.2
All Ages	100.00 (N=70)	100.0 (N=35)
Mean Age (years)	33.6	44.6

X^2 = 14.51; 2df; highly singnificant.

The **sex-distribution** of patients is more or less similar in the high and low endemic areas. In the high endemic area 58.6% of patients are males and 41.4% females. In the low endemic area 68.6% are males and 31.4% females. The lower percentage of females may be due to the fact, as many studies have indicated, that among women there is a lower incidence of leprosy. However, the fact that the National Leprosy Control Program is a male dominated one (all leprosy technicians are males) cannot be overlooked because the structure and nature of the program may in itself be responsible for under-detection of female patients. This may be an explanation for the large percentage difference of male and female patients.

With regard to **marital status** 82% (86 out of 105) of the patients had been married and out of the latter 87% were currently married, the remaining being widowed or divorced (divorce not being due to leprosy). Of those who never married 31% (6 out of 19) didn't do so because of leprosy, the remaining not having married due to reasons other than leprosy, such as, "not yet of marriageable age", "not employed" and "too poor". Since we did not find out whether those married had done so either before or after getting leprosy, it is difficult to conclude that the patients "not married due to leprosy" would be higher.

Community, Education and Landholding

These three variables are the main differentials that we are considering in this study. As we have seen elsewhere in this report, these variables are not only important differentials but also vary together. They are not independent of each other. Together they form a comprehensive indicator of status. Table 7.2 gives prevalence rates of leprosy by these three variables showing significant difference.

In case of community and landholding there is a fair amount of variation in pattern of distribution of leprosy cases in high and low endemic areas. In low endemic areas the upper castes and Muslims have the highest prevalence rates, whereas in the high endemic area the scheduled castes and tribes have higher rates of prevalence. However in the latter case the "upper" castes and Muslims constitute a very small proportion of the population and therefore the sample may be responsible for the wide variation. But there is also a possibility that the "upper" castes may not be registering with the state leprosy services (our sample is limited by this fact) for treatment because of their high social and economic position.

Table 7.2 : PREVALENCE RATES OF LEPROSY BY COMMUNITY, EDUCATION AND LANDHOLDING STATUS

CHARACTERISTICS	PREVALENCE RATE OF LEPROSY PER 1000 POPULATION		NUMBER OF CASES				PERCENTAGE OF PATIENTS +VE OR -VE OF POPULATION PROPORTION*	
			PATIENTS		POPULATION			
	HIGH ENDEMIC	LOW ENDEMIC	HIGH ENDEMIC	LOW ENDEMIC	HIGH ENDEMIC	LOW ENDEMIC	HIGH ENDEMIC	LOW ENDEMIC
A. COMMUNITY								
Upper Caste	0.0	1.88	0	17	153	9044	- 3.2	+ 7.6
lower Caste	13.73	1.41	33	6	2404	4256	- 3.4	- 2.8
Scheduled Caste	17.41	1.63	21	4	1206	2447	+ 4.7	+ 0.5
Scheduled Tribe	16.77	1.04	16	4	954	3830	+ 2.9	- 6.0
Muslim	0.0	1.76	0	3	53	1703	- 1.0	+ 0.7
B. EDUCATION								
No Schooling	16.94	1.97	40	24	2361	12151	+ 7.6	+11.5
Upto 7th	12.54	1.20	22	9	1755	7469	- 5.4	- 9.4
Secondary & higher	12.23	1.20	8	2	654	1660	- 2.2	- 2.1
C. LANDHOLDING								
Landless	11.44	3.2	18	14	1574	4320	- 7.3	+21.2
Marginal & Small peasants	17.87	0.82	38	8	2127	9725	+10.3	-22.5
Middle & Rich peasants	13.10	1.66	14	12	1069	7235	- 3.0	- 1.3
Total prevalence rate	14.68	1.60	70	34	4770	21280		

* A Positive value indicates that the proportion of patients in that subgroup are higher than what one would expect to obtain randomly. A negative value indicates that it is lower than what one would expect.

X^2 Values

1. Community: 51.09; 4df; highly significant
2. Education: 1.56; 2df; not significant
3. Land: 8.13; 2df; significant

In the low endemic area, where representation of various caste groups is adequate, it is the "upper" castes who carry a higher load of patient-population in proportion to their population in the study area. The difference is also possibly attributable to the fact that knowledge about leprosy is inadequate in the low endemic areas. Therefore, the "upper" castes, who place a great premium on purity and therefore may have a stronger stigma, may be registering (in the low endemic area) for treatment without knowing that they have leprosy. (Please note that while interviewing patients the term "leprosy" was never used - it was always "this disease for which you are taking treatment")

With regard to the distribution of patients on the basis of their landholding status Table 7.2 shows that landless in the low endemic area and the marginal & small peasantry in the high endemic area have a higher prevalence rate of leprosy. Both these groups carry a phenomenally larger load of patient population when compared with their groups' actual proportion in the population. Thus in low endemic area the landless constitute 20% of the population but 41% of the patients are from landless households, similarly in high endemic areas the small peasantry constituting 45% of the population has registered 54% of the patients in the area. The X^2 values in the case of caste and landholding with regard to difference between the high and low endemic areas are significant.

Interestingly the level of educational achievement is the only socio-economic variable (from among those selected by us) which has a similar distribution pattern of the patients of the two areas. In both the areas the highest prevalence of leprosy is among those who have never attended school, and in both the areas as educational level rises prevalence falls. This relationship is indeed very interesting because it is the only variable that has cut accross endemicity to reveal a well defined and significant correlation.

8

PATIENT'S DISEASE PROFILE

In this chapter we will discuss the entire experience of the patient with regard to the disease. How the disease was acquired? His/her perception of the disease and treatment of the disease. Please note that we will not be using any statistical significance test in this chapter because of the high non-response rate to various questions, as explained in a preceding chapter.

Onset of Leprosy

The identification of leprosy is related to certain physical changes experienced by those afflicted. What were these changes that the patients have experienced that led them to suspect or identify that leprosy had afflicted them? Please note again that we didn't use the term "leprosy" unless the patient himself/herself did so. In the high endemic area most patients freely used the word leprosy. Therefore when we use the term "leprosy" in the following paragraphs it is for the sake of convenience.

An overwhelming majority (over 2/3rds) in both the high and low endemic areas have stated "patch" as being the first physical change that they noticed or experienced which led them to suspect the disease. Table 8.1 gives the distribution of the various "first physical changes" reported by patients. The pattern of distribution is more or less similar in the high and low endemic areas.

Table 8.1 : FIRST PHYSICAL CHANGES ABOUT ONSET OF LEPROSY

PHYSICAL CHANGE	NUMBER OF PATIENTS (Percent)	
	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
Patch only	68.57	65.71
Patch with other changes	10.00	22.86
Deformity only	12.86	8.57
Did not Respond	8.57	2.86
All Cases	100.00 (N=70)	100.00 (N=35)

The proportion of patients reporting "patch only" as the first symptoms is similar in both areas. But those reporting other symptoms along with patch is more than twice in the low endemic area. These "other symptoms" or changes include swelling of face and feet, ulcers on various parts of the body, thickening of ear lobes and loss of eyebrows. This could probably mean that detection of leprosy takes place at earlier stages (presumably because of better knowledge) in the high endemic area. However, surprisingly in the light of the above fact, in the high endemic area the percentage of patients reporting onset symptom as "deformity" is substantially higher than in low endemic area.

Who first noticed these physical changes and suspected leprosy? More than half of the patients in both areas reported that they suspected it either on their own or through a family member or relative.(see Table 8.2) The paramedics identified 21% (17% in high endemic and 29% in low endemic area) and doctors 10% (14% in high endemic and 3% in low endemic area) of the patients before patients could suspect the disease on their own.

Table 8.2 : WHO SUSPECTED AND CONFIRMED THE DISEASE

	(PERCENT OF PATIENTS)			
	HIGH ENDEMIC AREA		LOW ENDEMIC AREA	
SUSPECTED AND CONFIRMED BY	SUSPECTING LEPROSY	CONFIRMING LEPROSY	SUSPECTING LEPROSY	CONFIRMING LEPROSY
Self and Family members	58.6	-	57.1	-
Paramedies (leprosy technician and MPW)	17.1	54.3	28.6	22.9
Doctor (PHC & Pvt.)	14.3	35.7	2.9	65.7
Did not Respond	10.0	10.0	11.4	11.4
All Cases	100 (N=70)	100 (N=70)	100 (N=35)	100 (N=35)

What emerges as significant in table 8.2 is that in both the areas a similar proportion of the first suspicion about the disease was made outside the health care delivery system. This can mean two things. One that awareness about the disease is the same. We know from an earlier chapter that this is not true. Second, and more likely, this similarity is possibly due to the unwillingness of those afflicted to accept the reality of getting a stigmatized disease (we have seen earlier that there is no

difference with regard to stigma in the two areas). And on the other hand it reflects on the relatively poor performance of the SET approach (atleast the survey part) of the Leprosy Control Program - that even in high endemic areas where the program has a high profile the first symptoms are mostly suspected by patients themselves. Table 8.2 also reflects that the leprosy technicians are possibly more active in low endemic areas but this fact needs careful interpretation because in high endemic areas there are doctors specially appointed for the leprosy program who are supposed to do active detection of patients. Thus a much higher proportion of patients are detected by doctors in the high endemic area than in the low endemic area, and this reason possibly reduces the detection tasks of leprosy technician (atleast in terms of proportion). In low endemic areas the doctors play an insignificant role in the leprosy program as far as active detection is concerned.

Related to the above we asked another question as to who, after suspicion of the disease, confirmed it to be leprosy? In Table 8.2 itself this distribution has been presented. In this case there is a significant variation between the two areas. In the high endemic area it is the leprosy technician who played a major role in "confirming" the suspicion about the disease, whereas in the low endemic area it is the doctor who did most of the "confirmation". It may be noted here that by "confirmation" we don't mean a bacteriological examination report but merely the fact of an assurance to the patient that the disease is leprosy. The bacteriological confirmation is a later event. This distribution, which is significantly different for the two areas, is reflective of who the "suspected" patients take into confidence for divulging that they have possibly acquired leprosy. Thus as the secrecy about the disease is greater in the low endemic area the patients tend to approach doctors directly because the doctor does not have routine contact with the community and therefore anonymity is assured. In the case of high endemic area where secrecy is not so much of a problem patients more often approach the leprosy technician, who is in more direct contact with the community, to confirm their suspicion of the disease since patients in this area may not care as much for anonymity.

After confirmation of the disease the treatment of all patients (except for one patient in the high endemic area who was wrongly treated for 3 years for some other disease) was started immediately. Of all the patients in the low endemic area only 2 (out of 35) started with private treatment but switched over to the PHC later (no reason given). In the high endemic areas

patients did not go to the private practitioner at all. All patients in the GMLF sample area (14 of the 70 high endemic cases) registered with the GMLF run leprosy unit and all patients in the Brahmapuri Leprosy Control Unit sample had immediately registered with LCU.

Further, of all the patients in the sample 42% (40% in low endemic area and 43% in high endemic area) had contracted leprosy within the "last five years" (1980-81 to 1984-85). Seventeen percent (6% low endemic 23% high endemic) had acquired the disease in the current year (1984-85) making for an **incidence rate** of 0.69 per 1000 population for both areas combined. For the same year, in the high endemic area the incidence rate was 3.35 per 1000 population and in low endemic area 0.094 per 1000 population. The **prevalence rates**, as indicated earlier, are 14.68 per 1000 population in the high endemic areas and 1.6 per 1000 population in the low endemic areas.(combined area 3.99 per 1000 population)

Treatment of the Disease and the Patients' Perceptions

The data with regard to treatment is of three kinds. One is about the type of treatment received, another about the information given to the patient about the disease and its treatment and the third is about the patient's perception of the disease and its treatment. This section will thus help us evaluate (from the patients' perspective) not only the treatment component of the National Leprosy Control Program but more importantly the much talked about education component of the program.

After confirmation of the disease as leprosy what was the **advice about treatment** given to the patients? An overwhelming majority of the patients in both areas said that no advice was given to them (see Table 8.3). They were only given the drugs. The few patients who did report that advice was given regarding the treatment said they were only told of the long duration of the treatment and the importance of its continuity.

Table 8.3 : ADVICE GIVEN ABOUT TREATMENT

TYPE OF ADVICE	PERCENT OF PATIENTS REPORTING	
	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
No Advice	75.7	80.0
About duration and continuity	8.6	8.6
About side-effect of drugs	0.0	2.85
About need for injection	1.4	0.0
Can't Recall	5.7	2.85
Did not Respond	8.6	5.7
All Cases	100.0 (N=70)	100.0 (N=35)

As regards advice about the disease itself an overwhelming majority of patients reported that no advice whatsoever was given to them either before or after treatment was started. Table 8.4 clearly provides evidence that where any advice about the disease is concerned whether with regard to its cure or deformity the information is most often not given and what is given in a few cases is not very helpful to the patients. With regard to spread of the disease only one patient from the high endemic area stated that he was explained the contagious nature of the disease - others said that no advice was given.

Table 8.4 : ADVICE ABOUT CURE, DIET RELATED TO THE DISEASE AND ABOUT DEFORMITY & CARE OF LIMBS. (Percent)

ADVICE ABOUT DISEASE	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
A: ABOUT CURE		
No Advice	77.1	85.7
Leprosy is curable	8.6	2.9
Can't Recall & did not Respond	14.3	11.4
B: ABOUT DIET		
No Advice	78.6	71.4
Avoid Liquor	1.4	-
Avoid 'garam' foods	4.3	17.1
Avoid onions	1.4	-
Can't Recall & did not Respond	14.3	11.4
C: ABOUT DEFORMITY		
No Advice	78.6	85.7
Regularity of Treatment to Avoid deformity	1.4	-
Massage of limbs	5.7	2.9
Can't Recall & did not Respond	14.3	11.4
All Cases	100 (N=70)	100 (N=35)

Table 8.3 and 8.4 then shows that the giving of advice about the disease and of its treatment is equally poor in both the areas and reflects on the quality of the education component of the Leprosy Control program.

Except for the GMLF sample in the high endemic area all patients received their drug dosage from leprosy technicians. In the case of the GMLF area the drug was administered to patients by a doctor led team. The drug dispensed in the low endemic area

was dapsone for all patients. In the high endemic area all, except three patients, were taking dapsone. The three exceptions, all in the GMLF area, were on a multi-drug regimen that included dapsone and rifampicin.

The patients were also asked as to what they felt about the treatment they were receiving. In the low endemic area 74% (26 out of 35) of the patients declared that the treatment they were receiving was right or adequate but in the high endemic area only 41% (29 out of 70) of the patients felt that it was adequate and another 41% said that they "did not know" about it being right or adequate. However, no one in either area said that the treatment was not adequate.

About the question on alternative treatment availed, one patient each in the high and low endemic areas reported such treatment. In the low endemic area herbal treatment and in the high endemic area ayurvedic treatment was reported.

We asked the patients if they knew of a better treatment being available. In the low endemic area 57% (20 out of 35) said "no" (the remaining said "Don´t know") but in the high endemic area only 11.4% (8 out of 70) said that no better treatment was available - However, only one patient said that there was a better treatment available (the remaining 69% said "do not know" and 18% did not respond).

Further, patients were also specifically asked if they had taken injections for this particular disease for which they were undergoing treatment. (This question was specifically added after our pilot interviews with leprosy patients revealed administering of injection by leprosy technicians and doctors). In the low endemic area only 2 patients (5.7%) reported receiving injections as treatment for leprosy but in the high endemic area as many as 15.7% reported having been administered injections for leprosy. In the low endemic area one of the patients recieved the injections from the leprosy technician and the other from a private doctor. Of the 11 patients receiving injections in the high endemic area 6 did so from doctors and the remaining 5 from leprosy technicians and MPWs. The difference between the two areas is possibly due to the fact that the high prevalence of leprosy in high endemic areas makes "injection-giving" lucrative for both doctors and paramedics.

From among those patients who said that they did not receive any injections as treatment for leprosy 22.5% in the high endemic areas and 16.7% in the low endemic area felt that there should be an injection made available as the latter can help speed up the cure, however 42.3% and 64% respectively, could not say whether injections were necessary.

With regard to the question about the need for a more potent drug like a capsule or an injectable 25% of the patients in the high endemic area and 16.7% in the low endemic area said "Yes" and 11% and 5.6%, respectively said "No" -the remaining said that they "could not say".

As regards **regularity of treatment** 51.4% of patients in the high endemic area and 31.4% in the low endemic area were regular. Table 8.5 shows the distribution of data regarding regularity of treatment.

Table 8.5 : REGULARITY OF TREATMENT (Percent of Patients)

REGULARITY	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
Regular	51.4	31.5
Irregular	28.6	11.4
No treatment currently	4.3	45.7
Did not Respond	15.7	11.4
All Cases	100 (N=70)	100 (N=35)

By regularity of treatment we mean that atleast 75% dosage was being consumed. This was checked by counting the tablets with the patient and comparing it with the period for which s/he had to consume it. The consequence was that those not responding increased in number.

Among those other than regular a very large proportion in the low endemic area (45.7%) were not taking any treatment. In the high endemic area "irregularity" was more common than "no treatment". Those who reported being irregular and/or not taking treatment were asked to give reasons. Table 8.6 shows that 60% of the patients in both areas indicated irregular supply of drugs or an inconveniently located health centre as being the cause of their irregularity or stoppage of treatment.

Table 8.6 : REASONS FOR IRREGULARITY OR STOPPAGE OF TREATMENT

(Percent)

REASONS	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
Fear of Stigma	3.6	5.0
Medicine Ineffective	14.3	-
Irregular supply of Drugs or Inconvenient location of health centre	46.4	80.0
Bad side effects of drugs	10.7	-
Tired of treatment or Forgetfulness	17.9	15.0
Treatment Expensive	7.1	-
All Reasons	100 (N=28)	100 (N=20)

Also Tiredness or Forgetfulness, because of the long duration of the treatment, is another reason cited for irregularity or stoppage of treatment.

Deformity and the Patient

Deformity is a major problem associated with leprosy. Infact deformity is the main culprit in stigmatizing (culturally) leprosy. Leprosy is largely associated as a necrotic disease, its other symptoms (especially where knowledge is lacking) are non-existent for the general population.

To the patients we asked two different sets of questions pertaining to deformity. One set to those patients who were not deformed and another set to those who had already experienced deformity. Table 8.7 indicates that 15.7% of patients in high endemic areas and 5.7% in low endemic areas were deformed. As indicated earlier; in the high endemic area a larger proportion of patients started their disease with deformity (9 out of 11) as compared to low endemic areas (1 out of 2).

Table 8.7 : DEFORMITY AMONG PATIENTS

DEFORMITY	NUMBER OF PATIENTS	
	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
YES	11	2
NO	59	33
TOTAL	70	35

How do patients perceive their deformity? In the high endemic area 4 out of 11 patients said they had acquired their deformity through some injury/wound and 3 patients said it immediately followed an anaesthetic patch. The remaining 4 gave reasons like they got deformity after a prolonged fever, exposure to cold and eating of pork. In the low endemic area, of the 2 deformed patients one said that he couldn't recall how he got the deformity and the other said it was the outcome of a long illness.

As regards change of attitude of people towards the patient after manifestation of deformity all patients (except one in high endemic area) in both areas said that there was no change in the people's attitude. The one exception said that people stopped interacting as earlier. This lack of change in attitude expressed by patients appears contradictory because deformity is supposed to be a major cause for stigmatisation.

With regard to the question of the patient's ability to work being affected both patients in the low endemic areas said that their working ability was not affected. In the high endemic area 8 out of 11 patients said that they could work normally' Of the remaining three, two said that they were not allowed to continue in their work and one said that the ability to work had been reduced.

From among patients who had not developed any deformity we asked a separate set of questions about their perception of deformity. Did they think their disease could lead to deformity? Table 8.8 shows that 34% of such patients in the high endemic area and 18% of patients in low endemic area felt that their disease could lead to deformity.

Table 8.8 : CAN DISEASE CAUSE DEFORMITY (Percent of Patients)

CAN DEFORMITY OCCUR	HIGH ENDEMIC AREA	LOW ENDEMIC AREA
YES	33.9	18.2
NO	0.0	3.0
Don't know and did not respond	66.1	78.8
Total	100.0 (N=59)	100.0 (N=33)

The responses in the two areas are more or less similar, and this possibly reflects the fact that the educational component of the Leprosy program has not had much effect, especially in the high endemic areas. However, since the "don't know" are very high no definite conclusions can be drawn. When asked if deformity could be prevented a majority of the respondents (58% in high endemic and 79% in low endemic) said that they did not know. Only 20% of such patients in the high endemic area and 9% in the low endemic area said that deformity could be prevented.

As indicated earlier in the chapter our intention here is not to prove statistically the significance of the variables included for study. Therefore any conclusions or arguments discussed may not be very definitive; but within the limitations of the data it is still very evident that the Leprosy Control Program is not as successful as desired and that it needs to be reviewed thoroughly in terms of the experiences of the patients. It is amply evident that the Leprosy Control Program is designed and executed without considering the context in which the patients are placed; also the objectives of the SET approach, especially the survey and educational component, are far from any significant achievement.

9

PATIENT'S INTERFACE WITH SOCIETY

In chapter 5 we had looked at the population's attitudes towards leprosy patients. We have seen that stigma of leprosy is almost universal and that there is no significant difference of harbouring stigma between low and high endemic areas.

When we interviewed patients, however, we found that they did not perceive any change in their normal or routine social interaction, except perhaps the attitude of the health personnel themselves. (See Table 9.1 A to H). This may appear as a contradiction vis-a-vis the population's attitude. Perhaps it is not, because the afflicted patient may take for granted discrimination in the situation s/he is placed in. This situation is similar to that of harijans and other lower castes in Indian society. And this aspect of the problem can only be understood through patient's life-history analysis using anthropological methods. The present study is restricted to the use of structured interviewing and therefore cannot venture to explain this contradiction.

Table 9.1 lists eight variables that may reflect changes in attitudes of the population to the leprosy patient after s/he got the disease. The table is clearly indicative of the fact that in the patients perception the health personnel are definitely showing a negative change in their attitude towards them. What were these changes that the patients were referring to? There were two types of behavioural changes that the patients identified. One is that the health personnel refuse to examine or see the patients (or visit them in case of paramedics) and the second is that they don't give proper information about the disease, its treatment and guidance about care of the diseased.

The **change in occupation** has been only in the case of deformed patients, all of whom said that because of the stigma attached to their disease they find it difficult to get paid work. In the high endemic area none of the patients reported that the attitude of the people had changed towards them after they got leprosy. In the low endemic area 2 patients (6%) said that villagers stopped interacting normally with them because of their stigmatised disease. In the high endemic area 2 patients (both deformed) stated that they were not allowed to go to the public well to get water.

On the surface these facts indicate that the patients don't face any significant stigma because of their disease. But data from household interviews gives clear evidence of wide prevalence of stigma towards leprosy.

Table 8.1 : CHANGES IN ATTITUDES TOWARDS PATIENTS AFTER GETTING LEPROSY. (PERCENTAGE)

AFTER GETTING LEPROSY	HIGH ENDEMIC AREA (N=70) YES	NO	CAN'T SAY & NON-RESPONSE	LOW ENDEMIC AREA (N=35) YES	NO	CAN'T SAY & NON-RESPONSE
A. Change in Attitude of Paramedies	44.3	35.7	20.0	34.3	54.3	11.4
B. Change in Attitude of Doctors (Including Leprosy Technicians)	27.1	52.9	20.0	22.9	65.7	11.4
C. Change necessitated in occupation	4.3	80.0	17.1	2.9	85.7	11.4
D. Change in Interaction with villagers	0	82.9	17.1	5.7	82.9	11.4
E. Changes with regard to Eating & Drinking at Public Eating Places	1.4	81.5	17.1	0	88.6	11.4
F. Changes with Regard to collection of water from public facility	2.9	80.0	17.1	0	88.6	11.4
G. Changes with regard to visiting place of worship	0	82.9	17.1	0	88.6	11.4
H. Patient's leprosy Affecting marriage of his/her children	1.4	85.7	12.9	0	88.6	11.4

INFORMAL INTERVIEWS OF SELECTED PATIENTS

These interviews have been conducted with patients who were willing to talk freely. Most patients, especially in low endemic areas, refused to talk at length. From the latter we got very sketchy information, some of which we have included in Appendix B.

In this chapter we give almost verbatim our detailed interviews. This is only the content of the main interview pertaining to the objectives of the study. Conversation to break the ice etc. and to conclude the interview has been excluded because it was not tape-recorded - only the main interview was.

We present these interviews unedited and without comments because we feel they speak for themselves. Further, we have not included these interviews in the main text to support our findings because these interviews are not detailed enough to arrive at generalisations.

ONE : Low endemic area in Aurangabad

Profile of the Patient (See xerox of the original patient record for details)

Date of Interview : 13th April 1985.
Patients occupation : Farmer
Year disease detected : June 1964.
Age at that time : 50 years
Type of disease : Lepromatous
Last Bacteriological examination (from ear): On 7-5-83 was positive
Out of 9 family members staying together 2 have leprosy

Q. Since how many years have you been living in `S´?
A. I´ve been born here itself.

Q. How much land do you own?
A. Fifteen acres.

XEROXED COPY OF PATIENTS RECORD.

82

राष्ट्रीय कुष्ठरोग नियंत्रण कार्यक्रम

कुष्ठरोगाचे उपचार कार्ड

कार्यक्षेत्रातील/कार्यक्षेत्राबाहेरील

क्लिनिक

~~क्लिनिक~~

ना.कु.के./एस.ई.टी./सेंटर निडयोल, एल.सी.यू. , जिल्हा औरंगाबाद

गाव/वॉर्ड/मोहल्ला : सेलापुरी उपचार केंद्र सेलापुरी

गाव यादी क्रमांक 2 रोगी सापडल्याची तारीख 26.6.87 उपचार सुरु करण्याची तारीख 26.6.87

कसा आढळला ? HS; SS; CS; HC; VR; RM; RC; RO

नाव श्रीमती शेषाबाई झोरड लिंग पुरुष वय/जन्मतारीख 40

पूर्ण पत्ता सेलापुरी व्यवसाय शेती

कुष्ठरोगासंबंधी तक्रारी (सूचक लक्षणे) आणि काळ :

(१) लाल चट्टे आले (२) तेलकट चमकदार त्वचा

(३) (४)

कुष्ठरोगाची सुरुवात कशी झाली

केंद्रापासून

चट्ट्यांची संख्या व आकार : (मागील ६ ते १२ महिन्यांच्या काळात) स्पष्ट/वाढणारे/कमी होणारे.

प्रकार : N (MA; T; P); N ? L (I; B); L नवीन/जुना.

आधुनिक औषधोपचार पूर्वी घेतला काय ? नाही/होय ; कोठे केव्हा

जर उपचार थांबविला असेल, तर, कारण

कुटुंबात पूर्वी व आता कोणी कुष्ठरोगी आहे का ? नाही/होय.

रोग्याशी नाते स्वतः रोग्याच्या घरातील इतर कुष्ठरोग्यांची संख्या 1

उपचार घेणाऱ्यांची संख्या 2 रोगी क्लिनिक/कोणत्या गाव व जिल्ह्यातून

घरातील सहवासितांची संख्या 2 तपासणीसाठी प्रथम भेटीची तारीख 26.6.87.

इतर काही माहिती

यादीतून नाव कमी करण्याची तारीख कारण : बरा झाला/गाव सोडून गेला/मयत झाला/चुकीचे निदान.

लिहिणाऱ्याचे नाव सौ सुमती डोंगे लिहिल्याची तारीख 27.7.91.-6.0

पडताळणी करणाऱ्याचे नाव व हुद्दा (१) रोग्यास तपासून

13/10/82 (२) रोग्यास न तपासता

संक्षिप्त रूपे :— HS = घरोघरची तपासणी ; SS = शाळा तपासणी ;
CS = सहवासित तपासणी ; HC = निरोगी सहवासितांची तपासणी ;
VR = स्वत: हून आलेला ; RM = बहुउद्देशीय कर्मचाऱ्यांनी पाठविले ;
RC = आरोग्य रक्षकाने पाठविले ; RO = इतरांनी पाठविले.

(शा.नि.) बाय २११४ (४,००,०००—४·७१)

13/10/82

चट्टे : संख्या—१, २, ३, ४, ५/अ. (अगणित) आकार ३ सेंटीमीटर पर्यंत/अ.

बधिरता : आहे/(नाही)

रंग : फिक्कट/(लालसर) कडा : स्पष्ट/(अस्पष्ट)

सपाट चट्टे : कोरडे/एकसारखे/(तेलकट)/चमकदार/गुळगुळीत.

उंचावलेले चट्टे : गोपूर्ण/फक्त कडा/फक्त मध्यभागी/मध्यभागी दबलेले/मध्यभागी बरा झालेला; कोरडा/खरखरीत/तेलकट, चकाकणारा, गुळगुळीत. केस गळणे; सुरकुत्या; व्रण.

डिफ इन्फिल : नाही/(आहे) (थोडे)/मध्यम/प्रगत; मुखवा विरळ : नाही/(आहे) 33%

गांठी : नाहीत/(आहेत) (लहान)/मोठ्या; (टणक)/जास्त

रिअक्शन पूर्वी आली का ? (नाही)/होय; कधीतरी थोडकी; सध्या आहे काय-(नाही)/आहे; फक्त चट्टयात/इतर ठिकाणी. भूज : हात/पाय; ; सांधेदुखी; मज्जादाह; कृष्णमंडलदाह.

ट्रॉफिक अल्सर : नाही/बरी झाली/आहे. हात—उ./डा; पाय—उ./डा.

6-5-71 -ve

जंतु परीक्षा : तारीख १९.११.६९ (कान) खवा; चट्टा; नाक. निगेटिव्ह/(पॉझिटिव्ह) +

30-11-71 +ve

बी. प्राय. ... 4.9.72 +ve

7-5-73 +ve

मज्जा	जाड		टेंडर (दुखऱ्या)		दुखणाऱ्या (वेदना-युक्त)		भुजलेले		शेरा
	उ.	डा.	उ.	डा.	उ.	डा.	उ.	डा.	
(१) अल्नर नर्व्ह	+	+	+	+					
(२) मीडीअन ..									
(३) लॅट. पॉप्. ..									
(४) पोस्ट. टी.बी. ..									
(५) इतर ..									

परिक्तीय बधिरता : नाही/होय ; हात : उ./डा ; पाय : उ./डा.

असमर्थता व विकृती	हलू शकणारे		हलू न शकणारे		आखूड होणे		शेरा
	उजवा	डावा	उजवा	डावा	उजवा	डावा	
हात							
पाय							

डोळे : लॅगॉफ्थॉल्मॉस : उ./डा. अंधत्व : उ./डा.

नाक : बसलेले

इतर महत्त्वाच्या गोष्टी :

(१) (२) (३)

औषधे :

औषधात बदल : कारण आणि तारीख

साल ६९ ... वय ६५ .... प्रमाण ३५७ .. मि.ग्रा.

महिना	१ला आ.	२रा आ.	३रा आ.	४था आ.	५वा आ.	नियमितपणा
एप्रिल	स्व	स्व	स्व	स्व		उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे						
जून						
जुलै						
ऑगस्ट						
सप्टेंबर						
ऑक्टोबर						
नोव्हेंबर						
डिसेंबर						
जानेवारी						
फेब्रुवारी						
मार्च						

साल ८० ... वय ६६ .. प्रमाण ३५ .. मि.ग्रा.

एप्रिल	स्व	स्व	स्व			उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे						
जून						
जुलै						
ऑगस्ट						
सप्टेंबर						
ऑक्टोबर						
नोव्हेंबर						
डिसेंबर						
जानेवारी						
फेब्रुवारी						
मार्च						

साल ८१ .. वय ६७ ... प्रमाण ..... मि.ग्रा

एप्रिल	स्व					उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे						
जून						
जुलै						
ऑगस्ट						
सप्टेंबर						
ऑक्टोबर						
नोव्हेंबर						
डिसेंबर						
जानेवारी						
फेब्रुवारी						
मार्च						

वार्षिक प्रगती अहवाल	वर्ष	वर्ष ८०	वर्ष
(१) जट्टे : आकार व संख्या वाढीस लागले/स्थिर/कमी झाले/बरे झाले.		नाही/ झाले	— —
(२) उलावलेले/तपाट (उ/त)		—	—
(३) लाली : आहे/नाही		—	—
(४) दुखऱ्या मज्जा . होय/नाही		नाही	—
(५) जंतुपरीक्षा . जंतू सापडले/नाही			
बी-आय			
रिॲक्शन किती वेळा १,१,२,३		—	
अनुपान . स्थिर/सुधारला अधिक गोल/बरा झाला/बिघडला.		सुधारला	सुधारला
रोग बधिरता : आहे/नाही		नाही	नाही
चेहऱ्यावरील/इतर अक्षर : होय/नाही		नाही	नाही
तरिष्ठाची सही व तारीख		[illegible]	२५/५/८१

तारखेसह प्रगतीची टिपणे

रिॲक्शन :

मज्जादाह :

कृष्णमंडलदाह :

रोग वाढण्याची चिन्हे :

जंतु परीक्षा :

हातापायावर जखमा/फोड

नव्याने आलेली परिवर्तीय बधिरता :

नव्याने आलेली विकृती आणि/किंवा अक्षर.

नमूद करण्याजोग्या इतर बाबी

टिपण.—जेव्हा रोगी स्वतः हजर राहतो त्यावेळेस "स्व" असे रकान्यात लिहावे. जेव्हा रोगी दुसऱ्याकरवी औषध घेतो, तेव्हा "प" असे योग्य त्या रकान्यात लिहावे.

साल ८३ ... वय ६५ ... प्रमाण ७०० ... मि.ग्रा.

महिना	१ला आ.	२रा आ.	३रा आ.	४था आ.	५वा आ.	नियमितपणा
एप्रिल	७					उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे	(७)	(७)	(७)	(७)		
जून	P/२	P/	P	P		
जुलै	P	P	P	P		
ऑगस्ट	P/६	P	P	P		
सप्टेंबर	P/६	P	P	P		
ऑक्टोबर	७	७	७	७		
नोव्हेंबर	७	७	७	७		
डिसेंबर	P/१	P	P	P	P	
जानेवारी	P	P	P	P		
फेब्रुवारी	P	P	P	P		
मार्च	P	P	P	P/२		

साल ... वय ८ ... प्रमाण ६०० ... मि.ग्रा.

एप्रिल	P	P	P	P	उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे	P	P	P	P	
जून	P	P	P	P/२८	
जुलै	P	P	P	P/२८	
ऑगस्ट	P	P	P	P	
सप्टेंबर	P	P	P	P	
ऑक्टोबर	P	P	P/२८	P	
नोव्हेंबर	P	P	P/१५	P	
डिसेंबर	P	P	P/१२	P	
जानेवारी	P	P	P	P	
फेब्रुवारी	P/६	P	P	P	
मार्च	P	P	P/२५	P	

साल १९८४/८५ वय ७१ ... प्रमाण ७०८ ... मि.ग्रा.

एप्रिल	P	P	P	P/३०	उपचार किती आठवडे घेतला ..... उपचार किती आठवडे आवश्यक होता ..... टक्केवारी .....
मे	P	P	P	P/२८	
जून	P	P	P	खोड	
जुलै	७	७	७	७	
ऑगस्ट	७	७	७	७	
सप्टेंबर	७	७	७	७	
ऑक्टोबर	७	७	७	७	
नोव्हेंबर	७	७	खोड	७	
डिसेंबर	७	७	खोड	७	
जानेवारी	७	७	खोड	७	
फेब्रुवारी	७	७	खोड	७	
मार्च	७	७	खोड	७	

....	C२-C३	४१	४१ (C४-C५)
(१) नवे : आलेर व संख्या वाढले आहेत/कमी झाले आहेत	कमी झाले		गाठींमध्ये जळ.
(२) [illegible]	—		गाठी
(३) गाठी आहेत/नाही	नाही		गाठी
(४) दुसऱ्या ठिकाणी : होणे/नाही	नाही		+ve
(५) बायोप्सी : झाली/नाही	+ve. C०१·८२		
जी-पस			
रिअॅक्शन किती वेळा ०,१,२,३	नाही		गाठी
अनुमान : स्थिर/सुधारला	सुधारला		सुधारली
अधिकाधिक/बरा झाला/बिघडला			
तारीख बोलावले : आहे/नाही	—		—
बदलेला पत्ता : आहे/नाही	नाही.		नाही
वस्तीची नही व तारीख			

तारखेसह प्रगतीची टिपणे

रिअॅक्शन :

मज्जादाह :

कृष्णमंडलदाह :

रोग वाढण्याची चिन्हे :

जंतु परीक्षा :

हातापायावर जखमा/फोड

नव्याने आलेली परिवर्तीय वधिरता ?

नव्याने आलेली विकृती आणि/किंवा अन्तर.

तपूद करण्याजोगा इतर भाग

टिपण.—जेव्हा रोगी स्वतः हजर राहतो त्यावेळेस "स्व" असे रकान्यात लिहावे. जेव्हा रोगी दुसऱ्याकरवी औषध घेतो, तेव्हा "दु" असे लिहावे किंवा रकान्यात [illegible] द्यावे.

Q. Is this entirely your own or distributed between brothers?
A. Yes. It's mine.

Q. How much of it is under irrigation?
A. One and half acres.

Q. When did you get married?
A. Around 1947-48.

Q. How did you acquire this disease for which you are taking treatment from the PHC?
A. I used to have trouble.

Q. What sort of trouble?
A. Used to get itching sometimes

Q. Where?
A. Here in the groin and rest of the body, and feet would become numb. And then white patches appeared in the lower back.

Q. Then, What did you do?
A. Started taking tablets.

Q. No. Not in that sense. Where did you go - to the PHC or dispensary?
A. first I went to Bhularam in Hyderabad. There is a big Mosque there.

Q. Did you pray for divine blessings?
A. No. They give medicines. I used to get swelling on my feet, hand, and face and people said its leprosy. At that time I was very worried, my children began keeping a distance and I'd be alienated from most situations - that is why I went to Telangana. I got medicines from there. Till I took medicine I felt fine, when I stopped, the swellings and itching would reappear.

Q. What was the medicine?
A. It was made from "wild almonds".

Q. How long did you take this medicine?
A. For two years.

Q. What did you do later. From where did you take medicines?
A. Later I began to take medicines from the government health centre. They gave tablets which I'am continuing today also.

Q. How serious was the ailment then?
A. No, not much, but the swelling on my feet used to be there off and on.

Q. Was your skin smear taken any time?
A. Two-three times they had cut a section of my skin and also had taken blood from my hand, feet and ear lobe. And the Bidkin PHU doctor would come sometime and take my blood sample.

Q. Did this happen before your wedding or after?
A. No. This happend years after my wedding.

Q. Did you have any problems in the village after getting this disease? ...Like people would keep a distance or would move away on seeing you?
A. Yes. At that time this problem was there. People would turn away on seeing me.

Q. If there was a wedding in your community would you be invited?
A. Yes. I would be invited but people kept their distance from me.

Q. Were you allowed in the mosque to offer prayers?
A. Yes. For that there was no problem.

Q. How many children do you have?
A. Three children. The eldest is in Bombay, and the younger two are staying with me here.

Q. Are you still continuing with the medicines?
A. Yes. I've become so used to it that it has become a habit. I can't forget to take it. Once when the PHU at Bidkin didn't have any drugs because of some problems then I went to the Medical college at Aurangabad. They directed me to their health unit at Paithan where I was examined thoroughly, and they gave medicines every 15 days. Later they made it monthly. Then when things got sorted out at Bidkin I began to continue taking medicines from them.

Q. Did you ever stop taking medicines?
A. No. Never. I haven't but others in the village had and I made them continue by getting medicines for them also.

Q. After you got the disease did you take any precautions, observe restrictions.
A. Yes. Definitely. I stopped eating fish and stale food and stopped sexual relations.

Q. The vessels that you use for eating and drinking - Are they separate for you or the same as used by other family members?
A. No. They are the same. Only in the earlier stages of the disease my vessels were kept separately.

Q. How do you feel now? Do you feel that the disease has improved or worsened?
A. Now I feel good. The disease has substantially reduced, infact almost disappeared. And fellow villagers call me and interact with me.

Q. So, now you don't have any problem.
A. No, now there is no problem. Why should I lie. But there is one thing that if I don't take the tablet on any day then I don't feel nice - its like an addiction, a habit. If I don't take the drug on any day then my bowels don't clear up. Therefore I have to continue taking the tablets.

Q. Have you gone to school?
A. Yes. But not like the one you have been too. I studied Arabic scriptures only.

Q. You have brothers?
A. Yes.

Q. They stay separately?
A. Yes. Even he takes these tablets.

Q. He also has the same disease?
A. Yes. After me he too got white patches on his body.

Q. Did you stay together earlier?
A. No. We stayed separately.

Q. Did your father or other relatives have this disease earlier?
A. No.

Q. Then how do you think you acquired this disease?
A. No. That I don't understand. When it started I was young. Hands, feet, face and ear lobes would get swollen, there would be burning sensations inside my body, and itching on my hands, feet and groin. And then white patches began to appear. Why all this happened, I don't know. (his wife adds : these people ate too many eggs, and fish and had too much of milk. After I came to this house after our wedding I found they consumed a lot of milk, eggs & fish and after some years these symptoms began to appear. This is the reason why he got this disease.)

Q. After getting the disease did you get any injuries?
A. Oh Yes. Many. When I was younger I would participate in sword fights and have as a result got many wounds all over my body.

Q. How did you treat them?
A. (Wife adds : He didn't do anything. No medicines, because that would hurt his macho image - only used cotton to cover the wound and tied it up. And then he would start getting rash and the wounds never healed properly.)

Q. Did you get red patches too?
A. No. Only small white ones.

Q. Does anyone else have this disease in your home?
A. Yes. My eldest son.

Q. Where is he?
A. He is in Ulhasnagar, Bombay where he works as a Mason.

Q. How did the disease start in his case?
A. He used to sweat a lot, especially while sleeping. And gradually he too started getting white patches, some time after I got them. But he had very few compared to me.

Q. Is he also still taking medicines?
A. Yes.

Q. Is he married?
A. Yes. He even has 4 children.

Q. Did he get this disease before or after his marriage?
A. Before his marriage.

Q. Were the white patches visible when he got married?
A. No. They were not obviously visible.

Q. Okay, now please tell me about Mr. 'R' the leprosy technician from Bidkin, Does he come here regularly?
A. Yes. He comes.

Q. How often?
A. Once a month Sometimes twice.

Q. What does he do when he comes?
A. He distributes medicines sometimes and examines people.

Q. What sort of medicines he distributes?
A. Two types, one white and one red.

Q. Does he gives injections?
A. Yes. When we go to Bidkin then sometimes he gives injection.

Q. Okay, when he takes a skin smear or blood sample from you, does he tell you why he is doing it?
A. Yes. He does. He says that testing of this will help them know for how long medicines have to be administered and in what dosage.

TWO : High endemic area in Wardha

Q. Where has your husband gone?
A. He has gone to our village.

Q. Which village?
A. Maangaon.

Q. Do you own any land? Do you work in the fields?
A. We do not own any land.

Q. Then where do you or your husband work?
A. We are blacksmiths.

Q. What work do you do?
A. We make implements.

Q. What sort of implements?
A. Agricultural implements.

Q. Is there work every day?
A. Every day in the sense that it is seasonal.

Q. Have you been doing this work right from the beginning, or did you till the land earlier?
A. We've been doing this work right from the beginning.

Q. How many children do you have?
A. We have one son and two daughters.

Q. What work does your son do?
A. He works in Wardha.

Q. What work does he do? Is he a blacksmith too?
A. No. He does whatever work he gets.

Q. Why doesn't he work as a blacksmith?
A. He cannot cope with it. He does other outside work.

Q. Why doesn't he stay with you?
A. How do I know? He doesn't feel like staying with us, so he doesn't stay.

Q. O.K. Now, do you have any problems these days?
A. Not much problems.

Q. Do you take tablets?
A. I was taking the tablets till very recently.

Q. Have you stopped taking them now, or do you still take them?
A. No. Now I've stopped.

Q. Since how long have you stopped?
A. About one or two months now.

Q. Did your doctor tell you to stop taking the tablets?
A. Yes, my doctor told me.

Q. For how many years did you take the tablets?
A. I don't remember, but I've been taking the tablets for 8-9 years at least.

Q. When you began to take the tablets, which doctor were you going to?
A. Dr. Joshi.

Q. What problems did you have then?
A. Not many problems really, but the skin on my face seemed knotted.

Q. Was only the skin knotted or were there patches too?
A. There were reddish patches also.

Q. Does anybody else in your house have these patches?
A. No.

Q. Does anybody else in your house take tablets like the ones you take?
A. Yes. My husband used to take them too.

Q. Does he still take them?
A. No.

Q. When did your husband stop taking the tablets?
A. He has stopped taking the tablets for the last two months or so.

Q. What problems did your husband have?
A. Now how do I know that? He knows what problems he has. We never ask him what problems he has and all that. He knows it.

Q. What colour tablets were you having?
A. I ate whatever was given to me.

Q. No, just tell me what were the colours of the tablets you had?
A. Red, white, yellow were the colours.

Q. Were you given just one type of tablet, or did you have different types of capsules, etc.
A. I was given capsules too.

Q. How many types of capsules were you given?
A. Only one type.

Q. How many capsules did you have?
A. I was given eight capsules a month. I had to have 4 capsules in a day; 15 days later, another 4 capsules.

Q. Who gave you the capsules?
A. The doctor gave the capsules. I had to eat them in front of him, or he would not give them at all.

Q. Did you feel any difference after you took the capsules? Did you feel any better?
A. How do we know? Why don't you check for yourself and see?

Q. O.K. How many people in your village have the same problem like you?
A. How do we know anything about the whole village? Now that you have come, why don't you move about in the village, enquire and find out. Why do you ask us about it?

Q. Where do you get water from?
A. From the well, there.

Q. O.K. Now you have completely recovered from the earlier illness you had. But do you know what that illness was called?
A. I don't really know what it is called.

Q. See, we fall ill very often. We have cough, cold, fever. All these are illnesses. Similarly what you were suffering from was also a type of illness. Do you know what it is called, its name.
A. We don't know anything. How would we know the name, etc.

Q. Alright. What do you think caused your illness?
A. What caused it? I got the illness after two of my children were born.

Q. No, not like that, what do you think was the reason?
A. After the second child was born, suddenly I started getting reddish patches on my skin.

Q. Do you know the causes for this illness?
A. No.

Q. What other problems do you have because of this illness?
A. My body itches, I have fever, hands and feet ache, I feel my body is burning from the inside.

Q. What else do you feel?
A. I don't know anything else.

Q. Do you know how many years you will have to take these medicines to get completely cured?
A. How can we tell? But we will have to take the medicines till we are completely cured.

Q. Do you have any problems after taking the medicines?
A. No. I had no problems at all after taking the medicines.

Q. How much money did you have to spend for the medicines?
A. None at all.

Q. You got all the medicines free?
A. Yes, upto now I have not spent a single paisa on medicines.

Q. Has your son completed his education?
A. No, he did not go to school at all.

Q. Why?
A. See, we had put him in a school, but he did not attend school at all. He used to take his books and his slate and tell us that he is going to school. But he would roam around somewhere and come home in the evening. We thought he was in school, but he never went there.

Q. Because of your illness, did you have any problems doing the work of a blacksmith?
A. No. My illness caused no problems in my work.

THREE : High endemic are in Chandrapur

Q. From where did you get these tablets?
A. From the private doctor.

Q. You get these tablets from government dispensaries too. Did you know this?
A. Yes. We know.

Q. Then why did you go to a private doctor?
A. I thought, I'll get better faster if I go to a private doctor.

Q. Do you take only these tablets, or do you take any others as well?
A. The doctor also gives me capsules and two months ago he had given me an injection.

Q. When do you take these 60 m.gm. tablets?
A. Once a fortnight.

Q. How much did you pay the doctor?
A. Rs. 65/-.

Q. How many tablets do you have with you?
A. For the next 3 months.

Q. After paying Rs. 65/- did you pay anything more?
A. Yes, I did.

Q. How much?
A. The second time I paid Rs. 42/-.

Q. What was the total bill like?
A. For these three months I paid Rs. 107/-.

Q. How much did you pay the doctor?
A. The doctor did not take anything.

Q. Why?
A. He gave me the bill only for the medicines.

Q. Do you have any problems, because of this disease?
A. No, I have no trouble at all.

Q. What is your educational qualification?
A. I have done my twelfth standard.

Q. What were you taught about this particular disease?
A. Nothing at all.

Q. Didn't any of your books upto the twelfth standard have anything on this disease?
A. I don't remember anything.

Q. Do you know anything about this disease?
A. No.

Q. Can you tell me the early symptoms of this disease?
A. Small patches develop on your skin. If this disease develop further unchecked, then even your fingers may wither away.

Q. Do you know why this happens?
A. No.

Q. Do you know what happens if you take the medicines and what happens if you don't take them?
A. I don't know anything in such details.

Q. When these smallish patches started appearing, where did you first go?
A. I went to the doctor.

Q. Which doctor did you go to? To the malaria doctor or the leprosy doctor?
A. I went to the leprosy doctor.

Q. Did he immediately give you any tablets?
A. No. First he only wrote down my name, etc. After a fortnight, he gave me the tablets.

Q. How many days after you first noticed the patches, did you go to the doctor?
A. After 15 days.

Q. So it is nearly 5-6 years that you have been taking these tablets?
A. Yes.

Q. Do you take these medicines regularly, or do you stop taking them some time?
A. I take the tablets regularly.

Q. Usually, people stop taking the tablets for some time and then start again.
A. No, I didn't do that. I used to take the tablets regularly.

Q. Did you run out of tablets any time?
A. No.

Q. If the government hospital didn't have any left, then what did you do?
A. No, this never happened. I take the tablets regularly before going to sleep.

Q. Did they ever take your blood when you went to the hospital?
A. Yes. They had also scraped the skin of my ear.

Q. How many times did they do this?
A. Only once.

Q. They didn't take it again, after the first time, did they?
A. No.

Q. Do you know what those people do with the part of your skin they scraped?
A. No. How would I know?

Q. Did they tell you the causes of this disease.?
A. Due to germs, they said.

Q. Which germs?
A. I don´t know.

Q. O.K., how many people in this village, have this disease?
A. I don´t know.

Q. Is this disease contagious?
A. Yes.

Q. What is the meaning of contagious?
A. I don´t know.

Q. Do you know anything about paralysis?
A. Yes.

Q. Is it contagious?
A. I don´t know.

Q. `Contagious´ means that, the disease may be passed from one person to another. You told me that leprosy was contagious. Has anyone else been affected by you?
A. No.

Q. Why not?
A. Because I know that nobody else in my own house has leprosy.

FOUR : High endemic area in Chandrapur

Q. How much land do you own?
A. I don´t have any land.

Q. Then, what does your husband do?
A. We have our beedi making unit.

Q. Do you make beedis yourself.
A. No, I don´t.

Q. OK. Do you take any medicines?
A. Yes.

Q. From whom do you take them?
A. From Dr. `J´

Q. Since when?
A. For the last 10 years.

Q. Did you go to the doctor yourself for this, or was he checking you and then he gave you the medicines?
A. I went there myself.

Q. Why? What was the problem?
A. I used to have small boils on my face; I used to perspire a lot. I used to feel very hot from inside.

Q. Did you first go to the witch-doctor or to a doctor?
A. First I used to take herbal home medicines.

Q. For how long?
A. A year.

Q. Didn't you feel better?
A. No.

Q. How much money did you have to spend? Do you remember how much?
A. No.

Q. Do you have any problems now?
A. Not much problem, but I feel my body burning.

Q. Which tablets do you take?
A. White (DDS 100 m.gms.)

Q. Have you been taking these same tablets right from the beginning?
A. Yes.

Q. Out of these ten years, do you think you had tablets for at least 5 years?
A. Yes, more in fact.

Q. Did you feel any better?
A. Yes, slightly.

Q. Does anyone else in your house have leprosy?
A. Yes. My husband and my daughters have it.

Q. Why, do you think, you got this ailment?
A. How does anybody know? Only God knows.

Q. Do you believe in God?
A. Everybody believes in God.

Q. Which Gods do you worship?
A. God is one.

Q. Some people believe in God Vithoba, some others in Lord Shankar.
A. No, no, not those.

Q. Then which Gods do you worship?
A. We worship only in Baba Saheb (Ambedkar) and Gautam Buddha.

Q. Do you feel you'll be cured?
A. Why won't we be cured if we take proper medicines?

Q. Are there newer and better medicines for this ailment?
A. We don't know.

Q. How many people in your village suffer from leprosy?
A. How do we know? I don't go around counting the patients.

Q. No. I mean do you know of people who have leprosy?
A. No.

Q. Do you have problems while cooking, while making bhakris?
A. No, no such problems.

Q. Does any nurse come to your village?
A. We don't know of any nurse.

Q. Are there Gram Sevikas in your village?
A. Yes, there are.

Q. What are their names?
A. I don't know their names.

Q. Have you taken any medicines from them?
A. No.

Q. Can leprosy spread from one person to another?
A. I don't know.

Q. In your house you, your husband and your daughters have this ailment. Do you know what caused it?
A. No, we have no idea about it.

Q. Have you taken any other medicine besides these white tablets?

A. No.

Q. Has anybody given you any different medicine?

A. No.

Q. Could you tell us if you know of any new medicine against leprosy?

A. I know nothing about it.

SECTION FOUR : APPENDICES

APPENDIX 'A' : A Note on the GMLF

The Background

The Findings

APPENDIX 'B' : Extracts from Group Meetings

Informal Interviews and Notes

APPENDIX 'C' : Schedules used for Structured Interviews

APPENDIX : A

A Note on the Gandhi Memorial Leprosy Foundation, Wardha and comparison with a Government run LCU.

The Background

The Gandhi Memorial Leprosy Foundation (GMLF) is a scientific research association having leprosy related work as its focus. It is one of the pioneer organisations in the country evolving various methods of leprosy control, treatment, removal of stigma, health education and so on.

The Wardha project of the GMLF is one of five such projects in different states (others are T.Narsipur in Karnataka, Mararikulum in Kerala, Chilakalapatti in Andhra Pradesh and Balarampur in West Bengal). Each of them is managing one Leprosy Control Unit (LCU) of the Leprosy control program of the government. The GMLF selected these areas primarily for the high prevalence of leprosy in the villages covered under the LCUs.

GMLF has been working since 1951 following four main operational philosophies: i) GMLF will not confine its work to any local areas to eradicate leprosy, ii) It will not do routine leprosy work merely to give relief to patients, iii) It will not engage itself in laboratory studies or highly sophisticated research confined to four walls but will do it in and with the community, iv) It will take up such work and evolve such patterns as will help others (government and private agencies) to expand work for better service to patients.

Its stated objectives are: a) To detect and register leprosy cases, b) To conduct survey, education and treatment, and c) To control leprosy by using sulphone tablets.

No fundamental changes have been made in these objectives in the last 35 years of its operation. This does not mean that the GMLF is not flexible enough to undertake research and activities in newer fields. For example, they have not stuck to sulphone tablets alone but are also experimenting with multi-drug regimes.

In the first year of the project's operation (1951-52) a staff of 4 persons comprising one medical officer, one trained leprosy worker, one clinic assistant and one peon were employed. The project did not take up medical work immediately. The staff approached villagers in 36 villages (then having a population of 17,588) to conduct a survey. While doing the survey they organised and addressed meetings of villagers to explain their plan of work and sought people's support and participation in their programmes. As an outcome of this interaction, three outdoor clinics were started in Sewagram, Jaipur and Yesamba villages. At that time the prevalence rate of leprosy was over 25 per 1000 population and today it is about 8 per 1000 population.

The GMLF started a Leprosy Referal Hospital in 1965 which provides both patient care as well as support to field staff. It has 132 beds, an out-patient department, a full-fledged laboratory and a physiotherapy unit.

The GMLF has gone beyond medical care of leprosy. It strongly believes in raising the community's consciousness about leprosy and since 1961 have been doing continuous health education work in an effort to remove the stigma associated with the disease. Presently GMLF has discontinued active case detection surveys and have intensified health education further so as to increase voluntary reporting. Presently 60% of the total cases are voluntarily reported.

The methodology employed in the GMLF in removal of stigma is through domicilary treatment and rehabilitation. In their area of work over the years the GMLF have not found any instances of social displacement of leprosy patients. They also give guidance to patients to solve their social and other problems and assure that there is no ostracisation or victimisation on account of leprosy.

The Health Education Unit in addition to helping reduce stigma provides training to doctors, paramedics, technicians and groups of general population (students, teachers, development workers etc.). The unit regularly organises public meetings and exhibitions on leprosy to inform people about leprosy and to help ridding society of its stigma towards leprosy. The GMLF also maintains close liaison with about 60 voluntary agencies. The Foundation has recently set up a social science research unit to carry out research into the social aspects of leprosy.

The Findings

In the preceding chapters we have done a detailed analysis of the general population's knowledge of leprosy and their attitude towards leprosy as well as the experience of leprosy patients. The analysis was presented as a comparison between the low and high endemic areas.

Here we look only at the data pertaining to the high endemic area to see if the intensive work of the GMLF has had any significant impact. Thus in the following paragraphs we present a comparison between the GMLF and the government run leprosy control unit located at Brahamapuri.

In the GMLF sample covered by us the **prevalence rate** of leprosy was 6.36 per 1000 population whereas in the Brahamapuri LCU sample it was 22 per 1000 population. This difference, as we have stated earlier, is due to the fact of intensive work done by the GMLF since 1952 (even before the commencement of the national Leprosy Control Program). GMLF has successfully brought down the prevalence rate of leprosy in the Sewagram area of Wardha from 25 per 1000 to 8 per 1000. Our sample confirms this lower prevalence.

Further, our findings reveal that detection of leprosy also takes place earlier in the GMLF area. We have seen in an earlier chapter that "deformity" as a starting symptom was reported more often in the high endemic area. This fact was surprising is the context of better knowledge about the disease in the high endemic area.

We see now that all the cases of deformity as the "first physical change" in identifying/suspecting leprosy have been reported from the Brahmapuri LCU area. (Table A.1) In the case of the GMLF area "Patch" as the "first physical change" was reported by 86% of the patients, whereas in the Brahmapuri area only 64% did so.

Table A.1 : FIRST PHYSICAL CHANGES ABOUT ONSET OF LEPROSY

PHYSICAL CHANGE	PERCENT OF PATIENTS	
	GMLF AREA	BRAHMAPURI LCU AREA
Patch only	86	64
Patch with other changes	14	9
Deformity only	-	16
Did not Respond	-	11
All Changes	100 (N=14)	100 (N=56)

Another differentiating factor about detection between the two areas is the much more active role of the doctor in the GMLF area. The doctor identified (initial suspicion) 43% of patients in our sample in the GMLF areas whereas in the Brahmapuri area the doctor was responsible for the identification of only 7% of the patients. Ofcourse, this difference is largely accounted for by the different approaches of the GMLF & govt. LCU. In the latter case leprosy technicians play a central role, the doctor prefering to stay immobile at the LCU. It must be noted that the LCU doctors are supposed to be involved actively in case detection work. In the GMLF case the doctor is actively involved in the survey and case detection work and the paramedic plays more or less a second line role, being more useful for follow-up work.

Interviews of the doctors and leprosy technicians of the Brahmapuri LCU reveal a highly callous attitude towards the implementation of the Leprosy Control Program. For the doctor the posting to a Leprosy Control Unit is a "punishment posting". The doctor is not interested in the work but will demand a "hazard" allowance because he is working in the field of leprosy. The LCU staff were vehemently critical of the Leprosy directorate for not giving the special allowance to the leprosy field staff when the leprosy directorate staff (who do only administrative work) were getting that allowance.

The leprosy technicians have no choice because they are specifically trained for leprosy work. But whatever little they are doing is quite commendable because they do it without any physical and psychological support of the medical and administrative staff of the leprosy directorate. The leprosy technicians complained about the target approach in collection of smears. This, they felt caused unnecessary pressure, forcing them to manipulate figures. The leprosy technicians also mentioned that the people and patients gave them adequate respect and considered them as "leprosy doctors".

This difference between the GMLF and the Brahmapuri LCU has been responsible in the field of leprosy control. Thus, we find that there is almost 100% regularity of treatment in the GMLF area as compared to only 41% in the Brahmapuri LCU area. (Table A.2).

Table A.2 : REGULARITY OF TREATMENT

REGULARITY	NUMBER OF PATIENTS GMLF AREA	BRAHMAPURI LCU AREA
Regular	13	23
Irregular	-	20
No treatment currently	-	3
Did not Respond	1	10
Total	14	56

The main reasons given by patients in the Brahmapuri area for irregularity of treatment is irregular supply of medicines (46% of patients reported irregular or no treatment), ineffectiveness of medicines (14%) and tired of the long duration of treatment (18%).

Thus, as far as the detection and treatment of the disease goes the GMLF scores substantially in performance over the government run LCU. What about the social aspects and the health education component that is supposed to be a significant component of both the GMLF program as well as the govt s SET approach?

Questions asked to patients about advice or information given to them by the concerned agency regarding treatment, cure, deformity and diet related to leprosy have thrown up unexpected results. The patients from the GMLF area have all stated that no advice whatsoever was given to them about treatment, cure, and deformity of the disease. Only one patient stated that he was advised to avoid liquor. In the Brahmapuri area a small percent of patients (10%) have reported that some information about treatment, cure, diet and deformity was given to them.

This was as regards the patient but what about the general population? What is the difference with regard to knowledge and stigma of leprosy? Again unexpected results show up. We have not found any significant differences between the GMLF and the Brahmapuri LCU area. (See Table A.3).

Table A.3 : KNOWLEDGE AND ATTITUDES TOWARDS LEPROSY

PERCENT OF POPULATION/PATIENTS

CHARASTRIISTIC	GMLF AREA	BRAHMAPURI LCU AREA
POPULATION		
1. Have knowledge of Leprosy	80	89
2. Have correct knowledge	84	82
3. Knowledge acquired through self observation and experience	97	95
4. Leprosy patients need special attention & isolation.	30	30
5. Will not allow leprosy patients to enter home.	70	91
6. Will not work with leprosy patients.	70	98
PATIENTS		
7. Doctor's attitude changed after patient got leprosy.	21	29
8. Paramedical workers attitude changed after patient got leprosy	43	46

Table A.3 gives a percentage distribution of important variables that we have discussed in earlier chapters. These variables are those we have selected to understand stigma towards leprosy. We have seen earlier that stigma of leprosy is almost universal. We did not find any difference between the high and low endemic areas. Here we see that the hypothesis of no difference holds true even where an agency has done intensive work in health education to get rid of the stigma.

This raises a question as to the nature of health education as well as, more seriously, whether stigma can be eradicated through behavioural changes when the social structure itself is stigmatised - when society itself supports a differentiated and discriminating culture.

APPENDIX : B

EXTRACTS FROM GROUP MEETINGS, INFORMAL INTERVIEWS, AND NOTES

We had held a number of group meetings and Conversational Interviews. These meetings were mainly held to establish a rapport with the community. Discussions were very wide ranging. Here we present extracts pertaining to only two issues casteism and leprosy.

CASTE DISCRIMINATION

Sarpanch of a village and social worker since last 25 years : Dalits should not wear good clothes. And why do they want more education.

From our notes: Buddhists (Neo-Buddhists) in 'T' village are still treated with contempt. They are not welcomed in caste Hindu homes. They are offered tea in separate cups. They are given water but not in any cup or glass - from a distance water is poured into their cupped hands... In the same village there is a Buddhist ANM staying in the Buddhawadi and working under a nurse who is a caste Hindu. She is asked to do only sweeping and cleaning work. Besides she only carries the "sister's" bag on domicilary visits. She has no other status than this in the health services hierarchy.

From a meeting in a Buddhist basti :

Q : What was the state of health facilities five/ten years back? Is there any difference now? Have benefits accrued from the reservation policy?

A : Casteist practices still prevail. If we fall sick, we mostly go to a doctor, sometimes, we resort to home remedies like oil massage. But it does not benefit... Govt. has given us food concessions. The level of education has gone up. Progress of schooling etc. is good. There is some progress of our village also. But more attention is needed towards casteist practices. It is always better if ten persons persuade people than only one. Our community is conscious of unity and organisation. It is always better to be organised. We do not encourage disputes, and adhere to the principles set out by Babasaheb Ambedkar...

....We are all backward. There is a gulf between people from our religion and other religions. There is only an unstable peace, and also there is discrimination. They discriminate against us in day-to-day common dealings and social gatherings. Like tea parties - they keep separate cups for us. For the sake of human consideration we talk to each other. We invite caste Hindus in most social functions but they don't come. Only teachers come if they are called.

....Dr `A' comes here. Not the Nurse. She has never visited our basti...When we have called her to attend serious cases (deliveries) she has never come. She always tells us to send the patient to the dispensary. When we cannot even drink the available water in the dispensary, how can we send the patient there?

She also behaves discriminatingly. Once we also filed a complaint. She visits other bastis but not our wadi. Once our Arogya Sevika (also a Buddhist) fell very ill and we sent a message to her to visit her. She refused to come. We reminded the nurse that the Arogya Sevika was part of the same staff, but it didn't matter! If they don't care for us when we need them, it is better we approach other doctors.

....The village leaders are hand-in-glove with the health and rural development bureaucracy. A good worker is always transferred. The earlier nurse was sympathetic towards us but she was transferred. Dr `A' used to take lunch with us and he too was transferred.

Extracts from our notes and group meetings : "We (mahars) live in one corner of the village. Whenever our well dries up we have to go to the main village. But we can't touch the well. The villagers pour water in our buckets. In the school also our children are made to sit separately from others. And the village Kotwal, who is always from our community, has to accompany any visiting govt. official and serve him 24 hours as a menial. And for this he get only 7 1/2 payali of jowar (approx. 18 kgs)once in a year".

....Discriminatory casteist practices are dominant in `S' village. "Dr `B' does not visit harijan patients. In the school, even though names of harijan boys are registered, they are not allowed to enter the school. `B' is a harijan woman. Her son `B' had a swelling on his left hand. And so he want to Mr. `P', the

MPW. Instead of giving him any medicine he told him to cut a frog and tie it around his his hand. This is the way govt. servants treat harijans". Doctors never visit their bastis, they say. In the anganwadi also whenever they distribute snacks, they make harijan children stand out of the room. "Similarly, Mr 'G' (gram sevak) comes to our basti, only when he is accompanying big people like you".

....In village 'T' we (researchers) decided to stay with a buddhist family. When the sarpanch got to know of this, he was resentful. We had broken protocol by not entering the village through him. Earlier our investigators had stayed in the sarpanch's basti. He immediately rushed to us and offered us a comfortable place. We thanked him and said that Mr 'M's' family (the Buddhists) had already made our arrangements. He didn't like it. He insisted that we should not eat with the buddhists and offered us his own hospitalising. We disappointed him again by telling him that eating arrangements had also been made by the same family in their own house. He was furious and marched away. For us it was a tense situation because as researchers we could not take sides; we were also worried that after our depature the buddhist family might face trouble. Mr 'M' requested us to go with the sarpanch because he too had been nervous of hosting upper caste urban people. We could not change our decision and we decided to tackle the sarpanch later. We got a warm response from the Buddhist community but the Marathas had become indifferent to us. Their curiosity about our 'eccenteric' decision was also apparent. We met the sarpanch later on and requested him to call a meeting of villagers. He was generally pacified and called a meeting ofonly those who belonged to his own caste. However a large group of Buddhists accompanied us. To gain the Sarpanch's confidence we began by asking him to tell us of his contribution to the village's development and apologised for breaking of village protocol But we maintained that we were happy at the Bouddhawadi. This pleased him and we got an insight into his personal history. He even publicly appreciated our breaking of social barriers to live and dine with the buddhists. But he was very clear about his opinion of what social placement the buddhists deserved. Learning from this we decided to always stay on neutral territory henceforth schools (during vacations), panchayat office or health subcentres. We also took care to see that at our meetings we didn't have a mix of castes, especially those with varying social hierarchy.

....In another village we encountered an incident that again highlighted discrimination based on caste. A brahamin child had fallen into a village well. This was seen by a neo-buddhist man whose immediate response naturally was to dive into the well and rescue the child since the latter could not swim. He saved the child. When the villagers got to know of this incident their response amongst other things was to perform a ritual purification of the well which had been "defiled" by an "untouchable". Neither the village administration nor the district authorities did anything about this though such an act (of expression of untouchability) is punishable under the Indian Constitution.

....(A village meeting in a harijan basti)

Q : Do you have adequate water facility?
A : Yes.

Q : Do villagers trouble you?
A : We face trouble from them. But we cannot speak out openly about it.

Q : Does malaria doctor (MPW) give you tablets if you have fever?
A : Yes.

Q : Does he visit your homes?
A : We have to visit him home, if we fall sick.

Q : Do you have to pay for medicines which he gives?
A : Actually no one goes to him. But we have to give him money sometimes...

Q : The govt. gives some help to families below the poverty line. Have you received such help?
A : No.

Q : They have given goats, help to construct houses etc. Have you received any such help?
A : No. We had received only a broom and rope for each one of us!

ABOUT LEPROSY

Health Worker...

Q. What sort of illnesses are common in your village?
A. These days measles is very common. There is an epidemic these days. But besides that, there are different illnesses too.

Q. What are the main common illnesses in your village?
A. There is also leprosy.

Q. How many people suffer from leprosy?
A. Many people do. It is more common in the nearby villages. As that village is big, the population too is more. As there are more people, there is more illness.

Q. What do you feel, is this disease increasing or is it less compared to say, some years ago?
A. These days it is less. It has not increased.

Q. If someone has this disease, what happens to him/her?
A. The person gets boils - sometimes big ones, sometimes small ones. The fingers start withering. Even there's some perceptible difference in your face.

A Group Meeting...

Q. What do you think about leprosy?
A. We do not know about that.

Q. How does leprosy begin? What are its earliest symptoms?
A. We don't know that. May be those whose relatives are suffering from it would know.

Q. May be not full knowledge, but you do have some idea of it, isn't it? See, since many people from your village are suffering from it, you would have some information about it, isn't it?
A. Patches start appearing. The face reddens. Fingers start withering away.

Q. But what are the initial symptoms? Do patches start appearing?
A. Yes, patches appear on the skin, but people try to hide these.

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Q. Now suppose, there is a patch on my neck, will you be able to tell whether it is leprosy or something else?
A. We don't have enough information about that.

Q. It is possible that you may later develop this disease?
A. yes, you can't say anything about that - whether a person will develop it or not.

Q. Alright. Is this disease contagious? Can one person get it due to another and another?
A. Yes, that is possible.

Q. Do people who have leprosy patients at home take any special precaution?
A. Yes, earlier elderly people used to tell us that we should not even drink water at a leprosy patient's home; that we should not eat food etc. cooked by them; that we should not touch the utensils etc. used by them. Otherwise, we too will suffer from leprosy.
We were also told not to marry into a house with leprosy patients.

Q. If a leprosy patient comes to your house, do you take him inside? A. No, I don't let him come in.

Another Group Meeting....

Q. Do leprosy patients come to your place?
A. Yes. They do.

Q. Do you let them come into your home?
A. They come home and associate with us as normal people do.

Q. Do doctors come to enquire about them, treat them?
A. Yes, doctors do come. They come from Wardha. They check and diagnose the leprosy patients in the school and give them tablets.

Q. Do the Sevagram doctors come to your village?
A. Yes. They come only to test the patients' blood. They meet the leprosy patients and take away samples of their blood.

Q. Which community has a greater incidence of leprosy?
A. Leprosy is more common among the Buddhists.

Q. Do you know, what causes leprosy?
A. I don't know.

Q. People who are suffering from it, might have told you?
A. No. Nobody has told me about it.

Q. Do you think you may get leprosy?
A. I have no idea. But may be I can get it.

One More Group Meeting....

Q. How many leprosy patients are there in your village?
A. There are quite a few, but can't say exactly how many.

Q. What causes leprosy?
A. I don't have any idea about that.

Q. Do you think there is a possibility that you too may get leprosy?
A. That depends upon our fate.

Q. Do you let leprosy patients come into your house?
A. They don't come over at all.

Notes From Researchers Diary....

....Group meetings in village `M' revealed that there was no one suffering from leprosy in their village. This was not true because there were two patients in Boudhpada (father and son) registered with the PHC. That people did not know about these patients reveals that secrecy is maintained by the patients themselves due to the stigma attached to leprosy. Also, it must be noted that the patients were neo-Buddhists (a scheduled caste), a community to which there is already a general social stigma attached.

....In `P', there were three identified and registered cases. Two of them were a childless married couple in their late forties and both earned their living through `mazdoori' (labourers). They did not own any land. The husband looked very normal but the wife had developed early deformity on her face. She associated her disease with menopause.

The wife had developed external signs of leprosy about ten years ago and her husband a little later. As a consequence both had moved away from the village and lived in the forest for six years surviving on forest produce and the husband doing odd jobs.

Both had begun treatment at the PHC and since then have been taking the treatment regularly. The husband stopped taking dapsone a year ago as the doctors declared him cured. The wife is still registered for treatment but admits that she has become quite erratic in taking the drug because she feels she is now cured. Both are currently living in the main village (infact neighbours of the "police-patil") with no apparent social boycott.

On being asked whether they were forcibly sent away from the village on contracting leprosy, they said that they left on their own accord and had the choice of staying on in the village. Our probing in the village revealed that they had been asked to leave by their family members (the husband's brother is a landowner).

The third leprosy patient was a seventy year old tribal who had also contracted leprosy about ten years ago. His leprosy was detected at the PHC when he had gone for treatment for another ailment. He is still taking dapsone. He has continued living with his family throughout but is isolated within the house. A separate room with an entrance at the back of the house has been provided to him. There is a half-sized door connecting his room with the main house. He has no regular interaction with the rest of the family except that he gets his two meals a day in his separate 'thali'. He washes his own clothes.

Group Meetings...

Q. Would you allow a leprosy patient to enter your home?
A. No.

Q. Suppose your friend gets afflicted by leprosy how would you behave?
A. If he is our friend then we would allow him enter our home. But if we serve him food we will do so in a separate dish.

Q. Why?
A. Because he may transfer that disease to us.

..Q. Are there any leprosy patients here?
A. Yes, One patient.

Q. Does he work?
A. Yes. He works on his own farm.

Q. Do village people invite him for public meetings? Do they allow him to sit with them or do they ask him to sit separately?

A. He attends meetings and sits with other people. People do not know about his disease and many do not know anything about leprosy itself. That is why they allow him.

A Health Worker...

Q. What are the symptoms in case of leprosy?

A. First a patch appears on the body. It starts itching and slowly that patch grows.

Q. How do you diagnose the patch?

A. There is no sensation at the place where patch appears. We have to prick it. Then we can understand. Then I tell the patient that the doctor has called him in the dispensary.

Q. Has the leprosy survey been done by going to every house in the village?

A. Yes. It was done. But whether they visited each and every home, I do not know.

Q. If a person is suffering from leprosy, would people visit his house?

A. People who know about it avoid visiting a leper's house.

Q. Are leprosy patients invited for social functions?

A. Yes. They are called. And these patients when they attend social gatherings, keep a distance from others and also they sit separately at a distant place.

Q. What are the main diseases in the village?

A. There are no major diseases. Only two leprosy patients are there.

Q. Who are they?

A. One is Mr. 'H' and other Mrs. 'D'.

Q. Is Mr. 'H's' son also suffering from leprosy?

A. No.

Q. What are the signs of leprosy on Mr. `H´´s body?
A. On his feet there is a patch which does not pain when pinched. And it is also showing on his face and fingers.

Q. Are there sores developed on his feet?
A. No.

Q. What about fingers. Have they been effected by this disease?
A. No.

Q. And what about ears?
A. There is swelling on his ears.

Q. Is he receiving medical treatment?
A. Yes.

Q. Since when?
A. It must be now two or three years. Ever since it was diagnosed he is taking treatment.

Q. Do you give him medicines?
A. No, he goes to Talegaon.

Q. Is it not a part of your duty to look after his treatment?
A. No. First, he went to KEM twice. Later on he went to public dispensary at Talegaon.

Q. And for the last how many years is Mrs. `D´ suffering from leprosy? A. Her fingers are disfigured ....

Q. Does she have children?
A. Yes.. two children. She has a son and a daughter and her husband.

Q. Do the family members isolate her and treat her separately or do they mix up with her as usual?
A. They live together.

Q. Did they not isolate and separate her?
A. No.

Q. Does she go to work on farm?
A. Yes. They have their own plot of land. Children go to work on others farm also.

Q. Does Mr. `H´ also have a plot of farm land?
A. Yes. He also owns a plot of farm land.

Q. Who else are there in his family?
A. His wife, two sons and two daughters.

Q. Do they live separate from him?
A. Recently I have told them to make separate arrangements for him. I advised them to serve his food separate from others.

Q. Are these two patients allowed to intermix freely in social gatherings? They are your relatives, do you take them inside your house or keep them out.
A. I take them at home.

Q. It is alright because you know about health and hygiene. But what about others? Do they allow these patients to sit with them?
A. Yes, they are allowed to sit.

Q. Both of them?
A. Yes.

Q. It means none drives them away...
A. No. No one does that sort of thing.

Q. Are they invited to attend social functions at others homes?
A. I have not enquired about this. And they also never mentioned any such thing. However there is one thing. She is not allowed to touch water or to put her hand in water. That is natural, if people see her palm, they will object.

Q. Have you ever seen them taking lunch at other peoples' houses?
A. No. I have not seen them.

Q. Now you have received training about health. But earlier what did people know about leprosy?
A. No. I do not know much. Earlier they had no knowledge about leprosy. There is leprosy in our village for the last 20 years. One leprosy patient comes from the neighbouring village. I do not remember his surname. His name is 'C' and he is a preacher. He always has his meals at various places. No one isolates him.

Q. Does he stay at the temple?
A. Yes, at the temple.

Q. Which temple?
A. I mean, he does not stay only at one temple. He moves around and joins people sitting in groups. No one drives him away.

Q. Has he been taking treatment?

A. I do not know. I have never asked. And who would ask him? I never knew also that he suffers from leprosy. He always wears socks and boots. It was by chance I came to know when I saw him removing his socks. I kept it to myself. I did not say anything to him. Also his skin, cheeks and nose shine.

Q. What about the prejudice that it is a hereditary disease and the patients' children get it without fail?

A. No. It is not true. See there is a patient from Koregaon. He has three sons, but no one has developed leprosy.

APPENDIX : C

SCHEDULES USED FOR STRUCTURED INTERVIEWS

The following two schedules were used for the study. Please note that the "household schedule" in the low endemic area was different in the sense that contents & questions were almost the same, except there were many more questions on various aspects of health in the low endemic are - for details see chapter 2.

The "Patient Schedule" was the same in both the areas.

I. HOUSEHOLD SCHEDULE

SOCIAL ASPECTS OF DISEASE AND HEALTH SERVICES IN RURAL MAHARASHTRA

Research Agency : The Foundation for Research In Community Health, Bombay.

ID NO : _____

1) Area :

1.1 Village : ----------
1.2 Taluka : ----------
1.3 District : ----------

2) Respondent Profile :

2.1 Name : ----------
2.2 Sex : ----------
Code : 1 = Male
2 = Female
2.3 Age : ----------
2.4 Education : ----------
Code : 0 = No schooling
1 = 4th completed
2 = 7th completed
3 = 10th/11th completed
4 = Higher education
5 = Graduation/post graduation

2.5 Marital Status : ----------
Code : 1 = Never married
2 = Currently married
3 = Deserted
4 = Separated
5 = Divorced
6 = Widowed

2.6 Occupation : ----------

Code : 00 = Non-Worker
01 = Student
02 = Housewife
03 = Paid domestic worker
04 = Paid agricultural worker & mol mazdoori
05 = Cultivator-cum-worker
06 = Cultivator only
07 = Artisan
08 = Self employed petty trader
09 = Other (specify)

2.7 Community : ----------

Code : 1 = Brahmin
2 = Maratha
3 = Other Hindu Caste
4 = Scheduled Caste
5 = Scheduled Tribes
6 = Neo-Buddhists
7 = Jains
8 = Muslims
9 = Christians

3) Household Profile :

3.1 House type : Roof : ----------
Wall : ----------
Floor : ----------

Code : 1 = Pucca
2 = Kuccha

3.2 Landholding _____
3.3 Irrigated land _____
3.4 Type of irrigation : Well : _____
_____
River : _____
_____
Caneal : _____
_____
Other : _____
(specify) _____

3.5 Assets owned : Shop (specify) _____
_____
Household Industry _____
(specify) _____
Bicycle _____
_____
Scooter, Motorcycle _____
_____
Watch-clock _____
_____
Radio _____

3.5 Assets owned : Sewing machine _____

Plough _____

Bullock Cart _____

Pump-set _____

Tractor _____

4) Births and Deaths in last five years in household:

4.1 Births -

Sr.No.	Name	Sex	Month & Year of Birth
(1)			
(2)			
(3)			
(4)			
(5)			

4.2 Deaths -

Sr. No.	Name	Age at death	Sex	Month & Year of death	Cause of death
(1)					
(2)					
(3)					
(4)					
(5)					

5) **Family Profile : (begin with head of household)**

5.1	5.2	5.3	5.4	5.5	5.6	5.7	5.8		5.9		5.10			5.11	
Sr. No.	Name of Person	Relation to head of house	Sex	Age	Education	Marital Status	No.of living children		Occupation		Illness in Last one month			Handicap	
							Male	Female	Main	Other	Type	Practi-tioner utilised	Expend-iture	Type	Deformity (if any)
1.															
2.															
3.															
4.															
5.															
6.															
7.															
8.															
9.															
10.															
11.															
12.															
13.															
14.															
15.															

6) Leprosy knowledge and stigma :

6.1 What do you know about leprosy?
1.
2.
3.
Record first three responses without any probe. After that probe about: patches - loss of sensation- thickening of ear lobe - loss of eyebrows - leonic nose and face - deformities.

6.2 How did you acquire the above knowledge?
(Probe if necessary)

6.3 How serious do you consider this disease to be?
(Probe if necessary)

6.4 Do you allow a leprosy patient to enter your house?
Code : 1 = Yes; 2 = No.
If NO, why not?

6.5 Do you or would you work in the same place as a leprosy patient?
Code : 1 = Yes; 2 = No.

7) Tuberculosis knowledge and stigma :

7.1 What do you know about tuberculosis?
1.
2.
3.
Record first three responses without any probe. After that probe about: sputum - blood - fever - weakness - debility - cough - chest pain.

7.2 How did you acquire this knowledge?
(probe if necessary)

7.3 How serious do you consider this disease to be?
Probe if necessary)

7.4 Do you allow a TB patient to enter your house?
Code : 1 = Yes; 2 = No.
If NO, why not?

7.5 Do you or would you work at the same place as a TB patient?
Code : 1 = Yes; 2 = No.
If NO, Why not?

8) Practitioner knowledge and utilization : (Utilization pertaining to all family members)

8.1	8.2	8.3	8.4		
Sr. No.	Practitioner	Knowl-	Utilisation in last 6 months		
			No. of times	Disease for which last utilised	Expenditure for last visit
1.	Private doctor				
2.	PHC/PHU				
3.	Vaidya/Hakim				
4.	MPW				
5.	ANM/Nurse				
6.	CHV				
7.	Bhagat/Mantrik				

II. PATIENT SCHEDULE

SOCIAL ASPECTS OF DISEASE AND HEALTH SERVICES IN RURAL MAHARASHTRA

Research Agency : The Foundation for Research in Community Health, Bombay.

1) Patient's Profile :

1.1 Name : ----------
1.2 Sex : ----------
Code : 1 = Male; 2 = Female
1.3 Age : ----------
1.4 Education : ----------
Code : 0 = No schooling
1 = 4th completed
2 = 7th completed
3 = 10th/11th completed
4 = Higher education
5 = Graduation/post graduation

1.5 Community (religion/caste) : ----------
Code : 1 = Brahmin
2 = Maratha
3 = Other Hindu Caste
4 = Scheduled Caste
5 = Scheduled Tribes
6 = Neo-Buddhists
7 = Jains
8 = Muslims
9 = Christians

2) Registration as Leprosy * Patient :

2.1 We came to know from the Sarkari Davakhana (LCU/PHC/PHU) that you are registered with them for any term treatment. Can you tell us in which year or how many years back were you registered?

2.2 With which centre are you presently registered?

2.3 Those who have change centres :
Where registered initially? ----------
Why registered there? ----------
Why changed to present centre? ----------

---

* Use the term leprosy only if patient uses it, otherwise use "this disease" or "disease for which you are taking treatment"

2.4 Those who took or are taking treatment from private practitioners:

Why did you take/are you taking treatment from private practitioners? ----------

Why did you stop taking treatment from private practitioner and are taking it from the Sarkari Davakhana now? ---------
---

3) Onset of Disease to Confirmation of Diagnosis :

3.1 What were the first physical changes related to leprosy experienced/noticed?

i) Any patch _____

ii) Loss of sensation in the area of patch _____

iii) Loss of sensation in the area other than patch _____

iv) Non-healing ulcer _____

v) Loss of fingers/toes _____

vi) Claw hand/foot-drop _____

vii) Thickening of ear lobes _____

viii) Epistaxis/nasal stuffiness _____

ix) Loss of eyebrows _____

x) Swelling and reddening of face _____

xi) Any other (specify) ---------- _____

3.2 Who first suspected the above changes to be due to leprosy?

i) Himself/Herself _____

ii) Family member(s) _____

iii) Neighbours _____

iv) Relative/Friend _____

v) CHV _____

vi) ANM/MPW _____

vii) Leprosy Technician : _____
a) During survey _____

b) By chance _____

viii) Doctor: a) Sarkari _____

b) Private _____

ix) Others (specify) ----------

3.3 Who confirmed that it was leprosy? ----------
Code : 1 = Leprosy Technician
2 = Govt. Doctor
3 = Private medical practitioner
4 = Agency doctor
5 = Other (specify) ----------

3.4 Did anyone tell you it was not leprosy and given you some other treatment (not for leprosy)? ----------
Code : 1 = Yes; 2 = No.
If Yes, Who? ----------

3.5 Doctor/technician has told you that you have leprosy and you are given treatment. Are you convinced that you have leprosy? ----------
Code : 1 = Yes; 2 = No.
If No, why do you think that the disease could not be leprosy? ----------

3.6 Looking back, how long (days/months/years) after the above physical changes were noticed, the leprosy was confirmed in your case? ----------

3.7 After leprosy was confirmed, what advise about the disease was given by the health person attending?
i) ----------
ii) ----------
iii) ----------

Record first three responses without any probe. After that probe the following:
i) Chance of cure: ----------
ii) Spread of disease: ----------
iii) Precautions to be taken to prevent the spread (specify any isolation advised) ----------
iv) About diet: ----------
v) About work: ----------
vi) About danger of deformity and how to prevent it: ----------
vii) Care of hand and feet: ----------
viii) About maintaining secrecy: ----------
ix) Who gave above advice? ----------
(mention the health person attending, eg: doctor, leprosy technician, etc.)

4) <u>Treatment</u> :

4.1 When did you start taking treatment?
(mention whether treatment was started immediately after confirmation diagnosis. If not, how long after the confirmation and reasons for delay in starting)
Year of starting treatment? ----------
How long after confirmation? ----------
Reasons for delay, if any? ----------

4.2 When treatment was started for the first time, what was the advice given about the treatment?

i) ----------
ii) ----------
iii) ----------

Record first three responses without any probe.
After that, probe for the following:

i) Duration of treatment (i.e., how long required to take): ----------
ii) Importance of continuity in consuming drugs for that duration: ----------
iii) What will happen if irregularity: ----------
iv) About bad effects (including any reaction) of the drugs: ----------
v) If bad effects, what to do? ----------
vi) Whether injections are needed for treatment? ----------

4.3 Where do you go to get medicine? ----------
Code : 1 = Supplied at home
2 = PHC/PHU/LCU
3 = Sub-centre
4 = Other (specify)

From whom do you get medicine for leprosy? ----------

4.4 What type of medicines are you taking?
(Do not ask direct question, ask patient to show medicines received by him and after comparing them with sample slip of drugs, note down the types of medicine)

i) Dapsone _____
ii) Rifampicine _____
iii) Clofazinine _____
iv) Other durgs _____

4.5 Apart from all these medicines (drugs), what other treatment have you taken for leprosy?

i) Herbal : ----------
ii) Ayurvedic : ----------
iii) Unani : ----------
iv) Homeopathic : ----------
v) Others (specify) : ----------

4.6 Do you feel that you are getting right type of treatment? _____
Code : 1 = Yes; 2 = No
If No, Why? _____

4.7 Do you think a better treatment is available? ----------
Code : 1 = Yes; 2 = No.
If Yes, What? _____
Where? _____

4.8 Are you getting injection for leprosy? ----------
Code : 1 = Yes; 2 = No
If Yes, from where? _____

If No, do you think injections are necessary to treat leprosy? _____
Code : 1 = Yes; 2 = No

4.9 Do you think capsules are necessary to treat leprosy? -------
Code : 1 = Yes; 2 = No

4.10 By counting tablets and asking informally about consumption of medicines, find out the regularity of the treatment : _____
Code : 1 = No treatment
2 = Irregular
3 = Regular
(Regular means consumption of medicine at 75% or more regularity. Less than 75% regularity is termed irregular consumption)

If irregularity or no treatment, ask reasons for the irregularity:

i) Does not believe it is leprosy ____
ii) Does not believe that medicines can cure leprosy ____
iii) Feels that he/she is not receiving right type of treatment ____
iv) Fear of being known as leprosy patient ____
v) Medicines not provided regularly at home ____
vi) No time to go the the health centre ____
vii) Health centre timings not suitable ____
viii) Health centre too far from home ____
ix) Does not like attitude of health personnel ____
x) Was not explained importance of regularity ____
xi) No medicine available at health centre ____
xii) Too costly ____
xiii) Bad side effects ____
xiv) Thinks he is not improving with the treatment ____
xv) Tired of prolonged treatment ____
xvi) Forgetfulness ____
xvii) Other (specify) ---------- ____

4.11 How much does the treatment cost you per month?
(includes cost of transport if medicines not supplied at home)
Doctors' fee/cost of medicine Rs. _____
Transport Rs. _____

5) Knowledge :

5.1 How did you get this disease? _____
_____

5.2 Which are the other ways one may get this disease?
_____
_____

5.3 Is any of your family members having leprosy? _____
Code : 1 = Yes; 2 = No
If Yes, Who? i) _____
ii) _____
iii) _____
iv) _____

6) Deformity :

(For patients not having deformity)

6.1 Do you think this disease can cause deformity? ----------
Code : 1 = Yes; 2 = No; 3 = Do not know
6.2 Do you think regular treatment can prevent deformity? -------
Code : 1 = Yes; 2 = No; 3 = Do not know
6.3 Can deformity persist after leprosy is cured? ----------
Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, Why? _____

(For patients having deformity)

6.4 When you starting treatment, did you have any deformity? ----
Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, What? _____

6.5 How did you get this deformity? _____
_____

6.6 Has peoples attitude changed after you developed deformity? _____

Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, in which way? _____
_____

6.7 Do you find any difficulty in your work due to the deformity? _____

Code : 1 = Yes; 2 = NO
If Yes, What? _____

(Probe : Effect on work efficiency)

7) Attitude of Health Personnel :

7.1 After they came to know that you have leprosy, has the attitude of any health person changed? In which way?

Health Person	Whether attitude changed	In which way
CHV		
MPW		
ANM & Nurse		
Leprosy Technician		
Private Practitioner		
Govt. Doctor		
Compounder		
Others (specify)		

7.2 When you go to Sarkari Dawakhana for the treatment of other ailments (for you or for anybody who is sick), how do the health personnel there behave with you?

Health Person	Behaviour
Doctor	
Nurse	
Compounder	
Others (specify)	

8) Social Aspects :

8.1 What work were you doing before you contracted leprosy? _____

_____

8.2 What is your present occupation? _____

Code : 0 = Non-worker
1 = Student
2 = Housewife
3 = Paid domestic worker
4 = Paid agricultural worker and mol mazdoori
5 = Cultivator-cum-worker
6 = Cultivator only
7 = Artisan
8 = Self employed petty trader
9 = Other (specify)

8.3 If any change in occupation (from 8.4 to 8.5), what necessitated such change? _____

_____

If leprosy not mentioned as one of the reasons for such change, ask was it due to leprosy? _____
Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, How? _____

_____

8.4 Do your family members know that you are having leprosy? ____
Code : 1 = Yes, all members
2 = Yes, some of them
3 = No

8.5 Are the people of your village aware that you are having leprosy? _____

Code : 1 = Yes, most of them
2 = Yes, some of them
3 = No

8.6 How many persons are having leprosy in your village? _____

8.7 Do the villagers move with you freely? _____
Code : 1 = Yes; 2 = No
If Not, Why? _____

_____

8.8 Do you participate in the congregations like public meetings, festivals, marriages, etc. taking place in your village? _____
Code : 1 = Yes; 2 = No
If No, Why? _____

_____

8.9 Do you take food or tea from food-stalls or tea-stalls in your village? _____
Code : 1 = Yes; 2 = No
If yes, do you get tea or food in the same plate/cup as others? _____

Code : 1 = Yes; 2 = No
If No, Why? _____

_____

8.10 From where does your family fetch water? _____

_____

8.11 How many families draw their water from that source? _____

_____

8.12 Do you fetch water for your family? _____
Code : 1 = Yes; 2 = No
If No, Why? _____

_____

8.13 Do you visit temples/churches/ mosques? _____
Code : 1 = Yes; 2 = No

8.14 If Yes, do you go along with others or separately?
_____

8.15 If Separately, why? _____
_____

8.16 If No, in Question 8.13, Why? _____
_____

8.17 Do Sarpanch and members of Gram Panchayat know that you have leprosy? _____

Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, has their attitude changed after they came to know that you have leprosy? _____

Code : 1 = Yes; 2 = No; 3 = Do not know
If Yes, How (in which way)? _____
_____

8.18 Are you married? _____
Code : 1 = Never married
2 = Currently married
3 = Deserted
4 = Separated
5 = Divorced
6 = Widowed

(If never married separated, deserted or divorced, find out whether that was due to leprosy)?
_____

8.19 If currently not married and of marriageable age, why?
_____

(If marriage planned or fixed, or married after contracting leprosy, find out whether spouse is of lower caste/class, is patient of leprosy, is cured from leprosy and whether relatives of spouse know you have leprosy?)
_____
_____

8.20 If currently married or ever married, how many children do you have? _____

8.21 If any of them of marriageable age, have they been married? _____
Code : 1 = Yes; 2 = No
If Yes, when was the last marriage performed? _____
If No, Why? _____
_____

(If marriage planned or fixed, find out whether spouse is of lower caste/class, is a leprosy patient, is cured of leprosy and whether relatives of spouse know that one or both parents are patient/s of leprosy)?
_____
_____

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